Disintegrating Assumptions

A study of the attitudes and actions of residential support staff as they relate to intellectually disabled people's experiences of community integration.

Lisa A. Mills

Doctor of Philosophy in Social Work
University of Edinburgh
1998

This thesis has been composed by me, and represents my own original work.

This thesis is dedicated to the memory of my Grandfather, Luther B. Mearig, who regrettably passed away before he could see me complete.

Abstract

Historically, evaluative research of community care for adults with intellectual disabilities has been largely concerned with outcomes related to skill development. As service providers have begun to aspire to providing 'values-led' service, broader evaluations of lifestyle have been undertaken. Often, evidence from these studies suggest that relationship networks for intellectually disabled people have been unsatisfactory. They typically remain socially isolated from the wider communities where they live, and they are often dissatisfied with the relationships and social opportunities available to them. Service providers and researchers alike are increasingly aware that relationship networks are the central factor which determines to what extent community integration is possible for intellectually disabled people.

A number of studies which have explored community integration suggest that support staff have a critical role to play in determining the extent to which the relationship networks of the intellectually disabled people they support are both rewarding and instrumentally significant. However, no study as yet has focused exclusively on exploring and understanding how the attitudes and actions of support staff are related to intellectually disabled people's achievement of community integration via these relationship networks. This research endeavour addresses this question in detail, through a mainly qualitative study which utilises interview, diary, and observation data. The study uses a primary sample, involving three intellectually disabled people and six residential support staff studied over a three year period, to generate provisional explanatory conclusions. These conclusions are then evaluated for their generalisability by comparing them to the findings from a less lengthy, repeat study of four similar samples, involving eight intellectually disabled people and eight residential support staff, from different geographic localities and sponsored by four different provider organisations.

The findings suggest that the attitudes and practices of residential support staff are often a hindrance to intellectually disabled people developing satisfactory relationship networks and achieving community integration. In particular, a combination of competing agendas, a culture of complacency toward community integration, and underlying attitudes of resistance among staff, all coalesce to form a significant obstacle to the facilitation of improved integration outcomes. This study makes clear the need to alter the assumptions on which community residential services currently offer support to people with intellectual disabilities, and stresses the need to define new objectives for the longer-term which are different from those initially adopted at the point of relocation. The study concludes by making recommendations about what new assumptions should guide the process of defining and implementing new objectives.

TABLE OF CONTENTS

Introduction

A quarter-century has passed since Michael Bayley (1973) first made the important distinction between care *in* the community and care *by* the community, drawing attention to the fact that community care, as both policy and practice, had taken little account of how to involve informal sources of care in the lives of those receiving formal services. In addition, it has been just over a decade since Roy McConkey published *Who Cares?*, a book which outlined the need to pursue care *by* the community and the potential that existed for doing so (McConkey, 1987). Yet, I find myself concluding that the need to undertake this study has been, not only a sign that little positive change has occurred, but also a sign that the barriers to ideological and practical change may not as yet, be sufficiently well identified and understood so as to provide a way forward. Consequently, this study's focus on the role of residential support staff considers an aspect of the issue which previous literature has only indirectly addressed, and which is likely to have the greatest influence generally, on the ultimate experiences of community living that people with intellectual disabilities (living in residential accommodation) will have.

In *Who Cares?*, McConkey describes the recommendations for action, which his research generated, as challenging "long-held but untested presumptions" and conflicting "markedly with existing practices" (1987, p. 14). Nearly eleven years later, I have referred to these presumptions as *Disintegrating Assumptions:* assumptions which underpin community care practice that are both *dis* - integrating (in that they undermine intellectually disabled people's opportunities to experience

increasing levels of community integration), and *disintegrating* (in that the passage of time, and the increased understanding of the reality of community care which the field has gained from this, has rendered many of these long-held assumptions suspect enough to demand a serious re-think.

I have adopted this perspective from what I myself have learned by the passage of time: that asserting the importance of ordinary community members' involvement in the lives of people with intellectual disabilities, and successfully convincing politicians and practitioners to embrace this, requires not just a positive argument for the vision, but also a persuasive argument about the fallacious nature of the current reality. It seems logical that when people can let go of the past, they will then be ready to embrace the future.

PART ONE.

The Context for the Study

CHAPTER ONE

"Setting the Scene"

Overview

This chapter offers a critical look at how community care has evolved for people with intellectual disabilities in Britain, with consideration given to both historical events and policy developments which have shaped community care for this group. Particular emphasis is placed upon illuminating the Scottish experience.

Part One: Historical events which shaped community care

The origins of community care

Most social historians recognise the Royal Commission Report of 1957 and the resulting Mental Health Act of 1959 as being the first instances where the term 'community care' was actually used.[1] Yet these policy statements were not calls for something new. They were rather, calls for a shift away from institutional care, which had, through a previous shift in philosophy, become the *model of choice* in the period following the introduction of the Elizabethan Poor Laws and the rise of the industrial revolution.

Prior to 1601 however, care both in and by the community was the norm. Although social welfare did not exist formally in these times and was not the responsibility of government, welfare which did exist did not involve either institutionalisation or segregation. The history of early Christians suggests that they took no steps to segregate those who were disabled (Wolfensberger, 1979). Those who offered assistance to people in need saw it as a great opportunity, with giving as beneficial for the giver as for the receiver. During much of the Middle Ages, charitable works were viewed as religious duty, and attitudes were benevolent. Initially, religious duty was practised informally by families and communities (Dinitto & Dye, 1987). When this informal assistance was not enough, religious commitment became more formalised, but remained an integral part of community life. According to Wolfensberger (1979), thousands of hospices were founded across medieval Europe which were run in people's homes or as part of churches.

Race (1995) describes the history of the non-industrial ages in Britain as characterised by less complex technical demands on people. Hence, distinctions in intellectual ability were not apparent, and "most villages were able to cope with the 'idiots' in their midst" (p. 46). Across the world and across sixteen centuries, there is clear evidence that assistance for those in need was voluntary and community-based. As well, those receiving assistance were treated with respect and dignity. When these basic principles underlying the provision of assistance changed, the rise of the institutional era began.

The institutional era

According to Wolfensberger (1975), the first sign of the institutional era was the large-scale segregation, which first appeared in Europe during the 16th century, in response to the rise of contagious diseases and epidemics. As well, across the Atlantic, the Puritans of North America looked with suspicion on any behaviour which was outside their strict norms, often explaining it in terms of the supernatural (p. 3). For quite different reasons, there was a growing international emphasis upon the danger that certain people may bring to the wider community: in Europe, danger to the body in the form of contagious disease; in North America, danger to the soul through supernatural possession. These sentiments were underlined by the tone of the Poor Laws of 1601, with its strong emphasis on indoor, rather than outdoor relief. Consequently, there were calls for benevolent charity to cease.

The industrial revolution which followed caused societies previously dominated by religion and collectivism to give way to strong individualism (Griffiths, 1990). Religious orders were eliminated during the Reformation; thus the hospices they ran also disappeared and were replaced by charitable foundations which hired employees for the first time (Wolfensberger, 1979). The whole ethos of caring for those in need became a career option rather than a moral or civic duty.

Institutions for people with intellectual disabilities

Initially, people with disabilities were considered deserving of welfare. The attitudes which prompted the rise of residential institutions for this group were quite different from the attitudes which sustained them. According to Race (1995), the first institutions for people with intellectual disabilities were built in a period of optimism, particularly regarding the education of the intellectually disabled. People

were placed in institutions because it was considered to be an atmosphere that made them more amenable to training.

By the end of the 19th century however, a number of factors arose which made both institutionalisation and segregation a conscious choice, motivated by strong negative sentiment. In the early part of the 19th century, there was increasing scepticism about intellectually disabled people's ability to learn (Race, 1995). Likewise, the rise of the eugenics movement raised fears about intellectual disability being an inherited condition. This evoked warnings about the dangers to society of uncontrolled reproduction by people with intellectual disabilities. Tredgold (1909), a significant proponent of institutionalisation, made numerous arguments for the inevitability of institutions:

> I have come to the conclusion that, in the case of the majority of the feebleminded, there is one measure, and one measure only, which will fulfil all these desiderata and which is at the same time practically possible, namely the establishment of suitable farm and industrial colonies...Society would thus be saved a portion, at least, of the cost of their maintenance, and more important, it would be secure from their depredation and danger of their propagation. (p. 104)

In 1913, the Mental Deficiency Act was passed, making it relatively easy to 'certify' someone as requiring institutional care. This led to institutionalisation which often lasted indefinitely. According to Race (1995):

> 'Certification' had a permanence about it, probably enhanced by the prevailing views of invariance of intellectual abilities and certainly compounded by the essentially subjective nature of the Act. The motivation behind the Act was segregation of undesirable social 'inefficients,' and to a large extent, this was achieved. (p. 49)

Many people who displayed any behaviour that was unacceptable found themselves institutionalised. When Hitler came to power in Nazi Germany, he took this

ideology to its ultimate conclusion, exterminating large numbers of disabled people who had been institutionalised. But Hitler was not alone in choosing this route; in a reprint of his 1908 *Textbook on Mental Deficiency*, Tredgold (1952) argued that it would be "an economical and humane procedure were their existence to be painlessly terminated." The foundation for permanent segregation had been firmly laid, and it seemed unlikely that this trend would change. Notions about the importance of providing welfare as an integral part of mainstream society had disappeared, and the role for the wider community was no longer one of acceptance and support.

The deinstitutionalisation movement emerges

Despite the fact that by 1950, the institutionalisation of people with intellectual disabilities, as a social policy, seemed firmly entrenched, a unique pattern of events emerged, described here collectively as the deinstitutionalisation movement, which triggered the recent policy shift to community care. The key factors associated with this movement in Britain are discussed here.

Initially, during the period surrounding World War II, much research was conducted with the population institutionalised and labelled as mentally defective. When the NHS was established in 1948, this further encouraged research. In many cases, positive findings were documented which suggested that improvements were possible across the population of people with intellectual disabilities.[2] In England, Professor Jack Tizard and his colleagues produced significant research on the potential of 'mental defectives'.[3] For example, Tizard and O'Connor (1952) concluded that hospitals were greatly underestimating the potential of people with

intellectual disabilities, while a second study (O'Connor & Tizard, 1954) showed that 50% of the sample studied did not require nursing care or supervision.

Early legal events in the UK also contributed to the move toward deinstitutionalisation. A string of cases were published by the National Council for Civil Liberties in 1951 which alleged wrongful detention under the 1913 Mental Deficiency Act (Race, 1995). Alongside of this, the first parents group - *The National Association for Parents of Backward Children* (now *ENABLE*) - was formed, which further publicised both wrongful detention and the gross inadequacies of the institutions that existed. These events, coupled with the wave of positive research, clearly influenced the tone of the Mental Health Act of 1959.

This Act provided a policy springboard for the deinstitutionalisation movement to gain further strength by including a clear call for the reorientation of services toward more community-based care. Yet little more than an ideology was expressed. The Act was largely reactive in nature, concerned with addressing the growing allegations of wrongful, permanent detention in institutions. As well, the Act was responding to a newly published report from the World Health Organisation (1954) which emphasised that legislation regarding admission and detention should be carefully considered and regularly reviewed. Consequently, the Act provided for patients to be admitted on a voluntary basis which meant compulsory detention was no longer the sole legal mechanism by which people could be admitted to institutions. Not surprisingly however, this did not reduce the numbers of people living in institutions.

Overall, the Mental Health Act did little to effect the development of alternative community-based provision. Despite the events that had led to the Act, there were

virtually no conclusive debates over community care by the mid-sixties. Jones (1975) suggested that no one cared enough about the problems of long-stay hospitals to insist that decisions be made. But then, in August of 1967, *News of the World* published an article containing serious allegations of abuse and neglect of patients at the Ely Hospital in Wales. The Report of the Committee of Inquiry (Howe, 1969) detailed the insensitive, abusive, and inadequate treatment of patients by nursing staff and concluded that the concept of community care had been insufficiently developed (para. 515). When the reality at Ely Hospital became known to the general public, people began to view the need for community care in a more urgent way. Meanwhile, other scandals around hospital care continued to hit the media until as late as 1978, further evidencing the conditions that existed in long-stay hospitals.[4] Martin (1984) concluded that the institutional model of care had developed serious problems at most every level.

In addition, following the lead set by Erving Goffman (1961) in his internationally significant book *Asylums*, two British authors published books which documented the nature of institutional life, but with particular reference to the experiences of people with intellectual disabilities. *Put Away*, the timely work of Pauline Morris (1969), followed quickly after the Ely Inquiry and confirmed the tragedy of hospital-based residential care. Morris expressed little hope that change could be effected within the bureaucratic structures and medical model of care that typified the NHS.

Then in 1971, *Patterns of Residential Care* (King, *et al.* 1971), largely considered to be the most influential of the Tizard studies, was published. It offered a recognition of the unique problems of institutional patterns of care for children with intellectual disabilities. The authors highlighted the fact that institutionally-oriented practices

were largely associated with hospital provision and nursing-trained caregivers, and they shared Morris' view that reactionary changes to hospital regimes in the short-term would not be sufficient to bring about change in the inadequate patterns of care that predominated. Professionals who had considered Goffman's work were open to the idea that institutionalisation had not been a humane or sensible policy choice (Kennedy, *et al.* 1994), and the works of Morris and Tizard furthered this position.

Subsequently in 1972, the Scandanavian normalisation principle, first advanced by Nirje (1969), gained international recognition. Wolf Wolfensberger's publication of *The Principle of Normalization in Human Services* (1972) went beyond the more philosophical nature of the Scandanavian theory, and provided detailed guidelines for evaluating habilitation services (Landesman & Butterfield, 1987). Like research of the time, Wolfensberger's theory levelled strong criticism at the institutional model of care for people with intellectual disabilities. His arguments stressed the importance of environment, and clearly inveighed against institutions as a suitable living environment for people with intellectual disabilities. The principle set forth a number of opportunities that people with disabilities should have access to:

> a) Normal routines of living (home, work, leisure).
> b) Normal developmental experiences of the life cycle (adulthood and retirement).
> c) Rights to freedom, choice, and self-determination.
> d) A heterosexual world.
> e) Regular community environments and facilities.
>
> (Schalock & Kiernan, 1990)

On the whole, Race (1995) concludes that there is little evidence to support the notion that normalisation has had a significant impact upon the pattern of services across Britain, except in the development of staffed ordinary houses for residential accommodation. However, Tyne (1987) argues that Britain did take a particular interest in the normalisation-based evaluative methods that Wolfensberger pioneered

in relation to service provision: PASS (Wolfensberger & Glenn, 1975) and subsequently PASSING (Wolfensberger & Thomas, 1983) were used as a basis for teaching normalisation principles and introducing normalisation-based evaluation to British services for people with intellectual disabilities.

During this time, a critical precedent was set in the United States Supreme Court *(Wyatt versus Stickney, 1972)* which made it illegal to institutionalise a person unless it was first shown to be the least restrictive habilitation setting (Taylor, 1988). This case coincided with a flood of new allegations of wrongful detention in Britain which raised serious human rights questions about the institutionalisation of intellectually disabled people. At the same time, the United Nations adopted the *Declaration of the Rights of Mentally Handicapped Persons* (United Nations General Assembly, 1972), which "indicated a growing national and international consensus about...the need to take positive action" (Malin, 1987, p. 32).

Conclusion

The collective voice of the deinstitutionalisation movement struck a chord with politicians who, by the late sixties and early seventies, were publishing policy statements that implied the time had come to begin a new era of community care. Since that time, numerous policy statements have been produced which have all impacted upon the process of developing community-based options for people with intellectual disabilities. This is the subject of the next section.

Part Two: Policy developments in community care

Introduction

Jones (1975) argues that the unique circumstances and needs of people with intellectual disabilities have often been overlooked in policies which have been written under the umbrella of mental health. Hunter and Wistow's (1987) recognition of the clear scarcity of policy documents relating specifically to community care for people with intellectual disabilities, especially since 1980 and especially in Scotland, seems to support this claim. However, two distinct policy phases can be discerned. While the seventies was a decade in which policies addressing community care for people with intellectual disabilities were relatively plentiful, after 1979 however, there has been a greater preoccupation with older people and people with mental health problems. The most recent policy initiatives have been triggered by concerns about the cost of services for older people. This overall pattern has had unique consequences in terms of how community care has developed for people with intellectual disabilities.

Early policies

Seebohm & Kilbrandon bring changes for local authorities

Not until almost a decade had passed since the appearance of the Mental Health Act of 1959 did additional social policy documents appear which addressed the need for community care. Prompted by a concern for the growing problem of juvenile delinquency, the Seebohm Committee in England and Wales, and the Kilbrandon

Committee in Scotland, were charged with "reviewing the organisation and responsibilities of the local authority personal social services...to consider what changes are desirable to secure an effective family service" (Home Office, 1968, p. 11). The Seebohm Report was, despite combining mental illness and intellectual disability into one category of 'mental disorder,' politically significant because it strongly supported care in the community for this group. Seebohm argued that most 'mentally disordered' persons were able to live with their families or in hostels, and recommended that local authorities take on responsibility for supporting these living options (p. 107). In contrast, the impact of Kilbrandon (SHHD, 1964) on the development of community care services for people with intellectual disabilities in Scotland was predictably non-existent, given that the committee focused exclusively on the needs of children.

A landmark policy is published

Better Services for the Mentally Handicapped, the White Paper (DHSS, 1971) which is recognised as the first significant community care policy document for people with intellectual disabilities, offered a twenty year plan to implement the policies of community care in England and Wales. While Jones (1975) considered the policy changes suggested by the White Paper as "simple and sweeping," the proposed changes in practice were said to be approached cautiously and the pace of change intentionally slowed (Booth, *et al.* 1990).

The White Paper recommended that hospitals should become places for treatment, not residential care. In-patient beds were expected to decline by 50%, while hospitals were to enhance their day-care and out-patient treatment programmes. In response to the declining number of hospital residential places, the Paper called for

local authorities to take over responsibility for providing residential care in small units like group homes, foster care, ordinary houses, or flatlets. The proposed increase in local authority provision was to be six-fold, with community care development phased over a 15-20 year period. As an initial step to decreasing the need for hospital provision of a non-medical nature, there were calls for an increase of 40,000 places in adult training centres.

The total cost was estimated at 120-130 million pounds. More money was expected to be forthcoming (DHSS, 1976). It was envisaged that capital investment would rise by 2% a year for the next ten years and that this would provide sufficient funding for the initiatives outlined in the White Paper. Financing was expected to shift from central to local governments in order to facilitate the development of community care.

The Scottish 'Blue Book' follows

If critics believed the White Paper to be cautious and change intentionally slowed, the Scottish 'Blue Book' (the White Paper's Scottish equivalent) was all this and more. While a reduction of hospital beds was part of the Blue Book recommendations, Scottish intentions behind this basic strategy were significantly different from those in England. According to Hunter and Wistow (1987), Scottish policy-makers were concerned with eliminating new admissions to hospital, while policy-makers south of the border were committed to both eliminating new admissions and transferring existing hospital patients to community settings. As a result, the legitimacy of hospital provision was heavily maintained in the report, and community care was expected to be suitable for only a small percentage of the total population of people with intellectual disabilities in Scotland.

This was reflected in the comparative targets set for hospital and community provision: .87 community and .67 hospital places per 1,000 in the White Paper, while the Blue Book recommended .43 community and 1.2 hospital places per 1,000. Scottish hospitals were to provide care for almost twice as large a proportion of the client group as compared with the remainder of Britain (Hunter & Wistow, 1987). Community care, rather than being portrayed as a significant revolution in service provision, was viewed in Scotland as a slight readjustment of the balance between hospital and community-based accommodation.

Problems with early efforts for change

Although the White Paper and the Blue Book recommendations were originally viewed as straightforward calls for varying degrees of reorganisation, making the recommendations a reality proved to be much more complicated than this. Local authorities were unprepared to expand community-based provision. The task of replacing hospitals with community care seemed ominous. Martin (1984) recognised that achieving change would require far more than national policies and resource allocation, while Seebohm (Home Office, 1968) was the first of many who would acknowledge that community care had become national policy with only a minimum of guidance to local authorities. Seebohm warned that if community care was to become a reality for people with intellectual disabilities, more money would need to be spent on developing local authority services; and the barriers between hospitals and local authorities would need to be removed if an effective service was to be provided. All of these issues figured into why early progress on developing community care was seriously constrained.

In 1972, Sir Keith Joseph pledged that until local authority services were built up, there would be absolutely no question of closing hospitals (Booth *et al.* 1990). Yet the White Paper and Blue Book seemed to suggest that even then, long-stay hospitals would remain open. Indeed, it was not just proposed that some existing hospital provision should remain. The White Paper called for 200-bedded hospitals to be built in the initial stages of policy implementation, while the Blue Book called for an additional 1100 hospital beds in Scotland. While it was unclear whether the local authorities could shoulder the responsibility of community care; these calls for more hospital provision added to the air of scepticism, and left many feeling bewildered about where community care was actually headed.

While there was strong criticism of the White Paper's stance on keeping hospitals open (e.g. CMH, 1972), in Scotland however, very little criticism of the Blue Book seemed to surface after its publication (except in relation to the role of voluntary efforts which is dealt with in the next chapter). This lack of criticism is significant, given that Scottish policy offered greater support for continued hospital provision than the White Paper. According to Hunter and Wistow (1987), unique to Scotland was the distinct lack of pressure exerted by the wider community to force the development of community care, particularly for people with intellectual disabilities.

Meanwhile, the reorganisation of the NHS in the mid-seventies, anticipated to boost the co-operative relationship between health and social services, caused upheavals that actually hindered the joint planning essential to the community care strategy. While south of the border, the NHS was nonetheless beginning to make moves to give up its status as the primary residential provider, in Scotland, the NHS proved to be a significant barrier to developments of community care. The "great

caution...among doctors about letting go of beds and embracing community alternatives" resulted in the Scottish NHS holding firmly to its role as residential provider, with levels of hospital beds over twice the number in England and Wales (Hunter & Wistow, 1987, p. 71).

Added to this already bleak scenario were problems with financial arrangements and incentives designed to stimulate moves to community care. In England, joint financing, introduced in 1976, made additional funds available to the NHS for collaborative projects with the personal social services to develop community care (Farquharson, 1984). In Scotland, similar arrangements were not available until 1980. In 1976, however, Scotland's advisory committee on the health service did produce a document entitled *The Way Ahead* (SHHD, 1976) which was intended to outline the priorities for the health service at that time. According to Gray & Mooney however, the document "amounted to little more than a reflection of the then current thinking" (1982, p. 228).

Taking stock brings renewed calls for progress

Clearly, local authorities were making very little progress, and in Scotland particularly, local authorities had no financial resources or guidance to do anything else. Not surprisingly, the greatest success in achieving the White Paper recommendations was in the provision of adult training centre placements. Overall, very little else changed as the result of the White Paper and Blue Book being published. Consequently, in the mid-seventies, Barbara Castle, the newly appointed Secretary of State at the DHSS, came under growing pressure to move community care forward. In 1975, she reacted by setting up both the National Development

Group for the Mentally Handicapped (NDG) and the Jay Committee as signs of central government's continuing commitment to the improvement of services for people with intellectual disabilities (Booth *et al.* 1990).

The National Development Group Report (NDG, 1978) expressed dissatisfaction with the progress that had been made. It pointed out that reductions in the number of people in hospital were occurring at the dreadful rate of less than 2% per year. According to the report, there were still 1300 newly admitted patients to long-stay hospitals each year, and there were 7000 intellectually disabled people, under the age of 18, who were still spending most of their lives in hospitals. The NDG called for progress to be forced, and for resources to be specifically earmarked. However, this report was not officially relevant to Scotland and so made little impact. Likewise, the Jay Committee Report (Jay, 1979), although still viewed by many as the most positive vision of community care that policy-makers have produced for people with intellectual disabilities, was to have little effect on the development of community care.

The Jay Committee report was viewed as positive for a two primary reasons: first, the Committee firmly adopted Wolfensberger's principle of normalisation; and second, the service principles included in the Jay report encouraged the use of generic services, informal community support, and advocacy. For the first time, this report addressed standards by which residential services should be developed. However, because the Report was never converted into a policy directive, its impact was greatly thwarted. Only a small number of progressive local authorities actually embraced the recommendations and used them to develop community care.

Meanwhile, Scotland was undergoing its own process of taking stock. Interestingly, alongside this quite optimistic policy development in England, Scotland saw the

publication of a report by the Programme Planning Group on Services for the Mentally Handicapped, which emphasised the fact that "many severely mentally handicapped persons are in need of protection from the community" and concluded that "the protective secure life of the hospital represents for them a suitable pattern of care."[5] The Report warned of the dangers of loneliness if people with intellectual disabilities moved to live in 'uncaring communities' and compared this to the richer social life enjoyed in hospital. Finally, the Report again reiterated past emphases on community care as a way of preventing new admissions, and did not envisage any meaningful transfer of existing patients to community-based accommodation.

A Better Life (SHHD & SED, 1979), the report on the state of community care for people with intellectual disabilities in Scotland, was published soon after the PPG Report and brought home yet again the degree of difference between Scotland and what was occurring south of the border. This report suggested a total of 1.8 residential places per 1,000, with 1.2 being allocated to hospital beds, and .6 to local authority accommodation in the community (para. 2.18). Although this represented a slight increase to the call for community provision made in the 1972 Blue Book, it represented no decrease in the level of hospital provision originally proposed. Likewise, emphasis on discharge remained weak, with the report maintaining that only 25% discharge from hospitals was possible. Overall, the report anticipated that 66% of residential places would continue to be provided by hospitals.

Finally, although the report offered significant support for joint planning and financial arrangements, especially to spur on the development of community-based residential care, this was not made a statutory requirement. With hospitals still intending to provide two-thirds of the residential provision on an indefinite basis, their willingness to finance local authority developments was even more unlikely

than in England and Wales. According to Hunter and Wistow (1987), the commitment to sustaining hospital provision remained the Scottish Office preference for at least another decade.

The eighties takes shape

After Jay, and just when it seemed that central government would have a clear mandate for creating legislation to stimulate the development of a positive model of community care, a political watershed came as the conservatives were elected to power. Consequently, no significant policy directives or legislation specifically addressing the development of community care for people with intellectual disabilities came from central government after 1979. Meanwhile in 1980, a report commissioned by the DHSS confirmed once again that community care had stalled, concluding that nine years on, the policies and visions of the White Paper were "still in their infancy" (DHSS, 1980). As a result, this new decade saw efforts turning almost wholly toward creating effective financial incentives to offset the previously inadequate funding available to local authorities, and the extremely ineffective arrangements for the transfer of funds from the NHS hospitals.[6]

Despite the lack of central government guidance, each country issued a single policy statement which informed the financial incentives later introduced. *Care in the Community* (DHSS, 1981) made it clear that 15000 intellectually disabled people living in English and Welsh hospitals could be discharged immediately if appropriate services in the community were available (para. 3.1). It also stated that people needing long-term care "should be looked after in the community" (para. 1.1). In addition, Wales followed with the *All Wales Strategy* (Welsh Office, 1983),

adopting normalisation, and making a comprehensive plan for development. No equivalent to *Care in the Community* or the *All Wales Strategy* was produced in Scotland. According to Hunter and Wistow:

> There was simply no debate along these lines in Scotland...
> We have shown that in terms of resources not only is Scotland better endowed than the rest of the UK but most of these resources have historically been used to maintain large numbers of long-stay beds...
> Despite the rhetoric of community care the pressure actually to develop alternative forms of provision to long-stay hospital beds is not present to the same extent as in England and Wales. (1987, p. 92)

It seems Scotland promised nothing and consequently achieved nothing (Martin, 1984). Scotland did however introduce a report on health priorities in 1980. While the *Scottish Health Authorities Priorities for the Eighties (SHAPE)* was more substantial than its predecessor, health had not worked in collaboration with social work on this report, and this only served to exacerbate "long-standing and acute structural divisions between health and personal social services" (Hunter & Wistow, 1987, p. 43). However, on a positive note, SHAPE (SHHD, 1980) was referred to by many health boards in Scotland when they set their own local priorities, and this did represent the first solid movement toward community care on the part of the Scottish NHS.

<u>The implications of local financial incentives and flexibility</u>

Ultimately, the financial incentives, which followed the early policy statements discussed above, were the most significant developments associated with the first half of the eighties. However, the various incentives introduced in each country brought mixed results. In 1980, four years after joint financing was introduced in England, Scotland introduced support finance. Relative to the funds made available in England through joint finance, the Scottish version offered only one-third of this

amount; and this was not to be in addition to health authority budgets but was rather to be taken from existing budgets. Compounding this, Scottish local authorities were expected to shoulder 40% of the cost of development projects from year one, and take on the full burden of cost by year five (Farquharson, 1984). This resulted in further disincentives to local authorities in Scotland. Despite making less money available, Scotland (like Wales) still possessed greater financial flexibility than England, where it was more difficult to re-channel adequate resources to community care. The existence of a block grant gave the Scottish secretary discretion to allocate expenditure to specific priorities. As well, rate support grants provided further flexibility for the Scottish secretary to match expenditure with local priorities. One would have expected this to facilitate the development of community care in Scotland, enabling it to surpass any developments being made south of the border. This however, did not occur in practice.

In Scotland, existing flexibility was not used to extend community care. Rather, it enabled politicians and the NHS to conspire to perpetuate a "more of the same" attitude toward developments of care for people with intellectual disabilities. According to Farquharson (1984), the lack of political will showed by the Scottish Secretary of State was demonstrated by the fact that "fewer political initiatives [were] introduced in Scotland to alter the balance of care between hospital and community, and substantially less resources [were] available to promote community care" (p. 2). Hunter and Wistow (1987) reflected on events in Scotland, concluding that "a degree of complacency and a commitment to system maintenance," has meant "there is no incentive, or compulsion, to take stock of the limitations of institutional provision or to look afresh at the goals of services for the priority care groups" (p. 94). The most damning evidence on this score was that joint planning, the process which could make use of financial incentives, was never made a statutory requirement.

While statutory joint planning for health authorities and social service departments in England and Wales was introduced in the late seventies, the same did not occur in Scotland. Despite the timely publication of a Scottish report on health and local authority relationships (SHHD, 1977), and a second three years later on joint planning and support financing (SHHD, 1980), no statutory requirement for joint planning resulted. This key difference in legislative mandates suggests yet another reason why community care in Scotland has been significantly slower to develop.

Financial incentives from central government are introduced

It wasn't until a dramatic shift in the benefit system took place in the early eighties that local authorities all over Britain were given new incentives to develop residential care in the community. Two key changes in the benefits system brought a huge increase in the monies available to the local authorities. First a supplementary benefit for private residential care was introduced; and second, board and lodgings payments were introduced for group homes or similar independent living schemes. Quite suddenly, it became economically attractive for the local authorities to provide residential accommodation to people with intellectual disabilities. In England, between 1980 and 1986, there was a doubling of the number of places in private residential homes (Booth *et al.* 1990). Unfortunately, Scottish community-based provision remained 50% lower than in England, despite these changes (Farquharson, 1984).

Despite chronic problems with joint planning leaving many elaborate plans for hospital closure largely unachieved (Wertheimer, 1986), the NHS finally began to focus more wholeheartedly on the need to support the development of community care. In the wake of the Griffiths Report on NHS management (DHSS, 1984), the

NHS introduced a general management structure which involved performance reviews. These set performance goals which specifically targeted reductions in long-stay mental handicap hospital beds. Meanwhile, the Minister of Health began pressing to get hospitals closed in specified time limits. At the same time, the NHS also experienced budget cuts, which made the prospect of saving money by closing hospitals much more appealing now than it had been in the past (Booth *et al.* 1990). Yet in Scotland, the impact of these developments was less pronounced than in other parts of Britain. Nonetheless, finally it seemed there were genuine incentives for local authorities to provide residential accommodation *and* for the NHS to close its long-stay hospitals. In Scotland however, prevention of new admissions was still the primary focus. By 1983, the number of adults resident in mental handicap hospitals was only marginally reduced, and as late as 1986, Scottish politicians were still suggesting that "hospitals will and will always have an important role to play in the care of the mentally handicapped" (Hunter & Wistow, 1987, p. 103-4).

The Rise of Contemporary Community Care

The late eighties was characterised by the emergence of strategic legislation coming from central government, that was designed to propel the rhetoric of community care forward. With financial incentives beginning to facilitate progress, central government took a directive approach which culminated with the passing into law of the NHS and Community Care Act in 1990. Two significant policy statements set the tone for this legislation.

Agenda for Action

In his report, *Community Care: Agenda for Action*, Griffiths recommended that local authorities should co-ordinate rather than provide services (Griffiths, 1988). This, combined with the political agenda of the conservative party, led to a vast expansion of private residential provision in England and Wales. With this, there came a significant rise in the number of provider organisations, many of whom had adopted normalisation principles and were developing projects based on staffed ordinary houses (Race, 1995). In addition, independent living projects were developing at a rapid pace in England and Wales (Booth *et al.* 1990). In Scotland however, the majority of community provision remained firmly rooted in the group home model (Kennedy *et al.* 1994). Indeed, Scottish local authority provision was more likely to be on the scale of hostel accommodation, and some voluntary providers, although increasing in line with Griffiths, pursued similar models of care. Even today, almost a decade later, very few moves beyond either of these models have occurred in Scotland, despite the fact that as early as 1984, the United States and Canada were already beginning to question the superiority of the group home model, especially in relation to social integration (Kennedy *et al.* 1994).

Caring for People

Griffiths' report underpinned the White Paper *Caring for People* (DoH,1989), which appeared a year later and laid the groundwork for the system of community care that exists today. For people with intellectual disabilities, this White Paper's philosophical underpinnings were very similar to those which appeared in the Jay Report ten year earlier. The concepts of individualism and choice were intended to

bring greater empowerment for all community care groups, and to:

> *enable people to live as normal a life as possible in their own homes or in a homely environment in the local community;
>
> *provide the right amount of care and support to help people achieve the maximum possible independence and...help them achieve their full potential;
>
> *give people a greater individual say in how they lead their lives and the services they need to help them to do so.
>
> (Ritchie, 1994, p. 8-9)

The practical suggestions for change which the White Paper introduced were numerous. However, only four recommendations were implemented. These included: community care planning; the separation of purchaser and provider; assessment; inspection units; and complaints procedures. The NHS and Community Care Act of 1990 gave legal status to these five areas.

The NHS and Community Care Act

In the spirit of Griffiths, the NHS and Community Care Act of 1990 included the first legislative mandate for local authorities to encourage the development of alternative providers and use these quite heavily in implementing community care policies. The Act also instructed each local authority to design its own plan to implement community care legislation. This had particular implications for Scotland, since the lack of service planning in social work throughout the country had long been considered a significant hindrance to the development of community care (Hunter & Wistow, 1987). The Act further called for local authorities to introduce 'representation' procedures for consumers, and widened the responsibility of local authorities to inspect residential accommodation. Finally, the Act called for local authorities to assess the needs of any person for whom the local authorities have a duty to provide community services. In addition, a significant financial

change appeared in the Act which spurred the development of community care across Britain. The transfer of funds from the DSS to local authorities, for new residential care clients, was planned for April 1993, and consequently many residential providers set up community care projects to pre-empt this change.

Despite this, change in the provision of service for people with intellectual disabilities has been slow. However, the proposals in the 1989 White Paper and the consequent legislation in the NHS and Community Care Act provided greater political legitimacy for the growing self-advocacy movement among people with intellectual disabilities. The importance of advocacy was first underlined through the recommendation for authorised representatives in the Disabled Persons Act of 1986, but this provision was never implemented. Yet when the NHS and Community Care Act specifically linked the planning and provision of services with the need to consider the views of service users, this was, for people with intellectual disabilities, a concrete manifestation of the rights given to them by the Disabled Persons Act. As a result, the impact of pressure groups, especially in Scotland, has been more significant in recent years, which has positively influenced the expansion of community-based care.

Chapter Conclusion

Where are We Now?

For the most part, the legislation of the 1990 Act has been implemented. In April of 1993, the planned financial changes outlined in the Act took place. The remainder

of the 1990's has seen welcome progress for people with intellectual disabilities, particularly with regard to hospital closures. However, this progress is now beginning to be called into question.

While many agree that finance, both the amount and availability, is central to the development of any new services, in retrospect, it seems that financial incentives have been the driving force in bringing about deinstitutionalisation and the rise of community care for adults with intellectual disabilities in Britain. Despite the seventies being filled with useful policy statements about the philosophical reasons for promoting community care, little changed as a result. In the eighties, a variety of financial incentives, accompanied by very little in the way of policy for people with intellectual disabilities (except in Wales) made community care develop. One wonders if many may have lost perspective on the philosophical vision behind community care for adults with intellectual disabilities, as real changes occurred on the basis of pounds and pence rather than values and sense.

Where is Scotland?

It is questionable whether Scottish politicians and professionals ever embraced the philosophical intentions of community care for adults with intellectual disabilities. It is certainly true that community care north of the border has failed to develop as it has in England and Wales. In Scotland, the combination of a strong allegiance to hospital provision, limited policies and financial incentives which have not been firmly supportive of community care, and local authority freedoms to choose spending priorities with little political pressure or guidance from the Scottish Office, have collectively made community care a struggle to achieve. Hence, in the

mid-nineties, the largest of the long-stay hospitals for people with intellectual disabilities in Scotland are just beginning to engage in closure processes.

This extremely slow progress is certainly due to a lack of resources and support for the development of community care, and may also be due to what Hunter and Wistow (1987) refer to as the Scottish "care worn and world weary" state (p. 60). Where freedom and flexibility have prevailed, Scotland has reacted with caution and tradition.

Implications for this Study

So what can one interested in studying community integration take from all of this? Despite nearly thirty years of policy on community care, large scale deinstitutionalisation is just beginning in Scotland, and with this has come a *preference* for community care which is relatively new to Scottish services. For many years, both politicians and practitioners held firm to a belief that hospitals offered the best form of care for this group. The segregation that was a consequence of this position was readily accepted and largely unquestioned. Therefore, it is not surprising that community integration, as a principle for service delivery, might not be among the priorities of either Scottish policy-makers or service providers. This seems evident in the current state of services.
Local authorities remain heavily committed to the hostel and group home models as community-based alternatives. To a large extent, private and voluntary organisations have followed a similar line. In many ways, the amount of time and energy that has been required simply to leave hospitals behind has meant that it may be unreasonable to expect many providers to have made the shift from focusing on

where they provide to *how* they provide. Yet there is significant evidence already available that suggests that even for those who have made the move to a local community, the notions of community living which have been suggested in more progressive social policies, and which are increasingly being acknowledged as the way forward, still remain largely unachieved.

In particular, the Jay Committee made two significant recommendations which suggested the vision of community care they wished to see for people with intellectual disabilities. First, they emphasised the fact that "mentally handicapped people have a right to enjoy normal patterns of life within the community;" and second, they went on to assert that in order for this to be possible, these people "will require additional help from the communities in which they live...if they are to develop to their maximum potential" (1979, p. 35). These recommendations reflect an assumption that both *where and how* services are provided are critical to the success of community care. As the role of the wider community is increasingly endorsed by more central government policy, it becomes essential to consider, within *how* services are provided, both the importance of community integration and the role of the wider community in making community care an effective and positive alternative to the institutional era for people with intellectual disabilities.

Yet developing community care out of the ashes of the institutional era may not be as daunting a task as many presume. History suggests that this era, in the grand scheme of things, was relatively short-lived. It will have spanned less than 300 years, with community care bringing a close to many long-stay hospitals by the end of the twentieth century. The whirlwind that followed the industrial revolution, and brought about the international commitment to institutionalisation, seems to have been dismantled with equal swiftness. In retrospect, the institutional era seems to be

represented in the literature as a mountain whereas in historical terms, it has figured more like a mole hill (Wolfensberger, 1979). Meanwhile, the often neglected majority of history suggests that prior to the rise of institutions, there was evidence that up to sixteen centuries passed during which people in need were treated humanely, in their own communities, and through the voluntary efforts of other community members. The importance of community integration and the role of the wider community in sustaining this was and continues to be indisputable.

By viewing the challenge to develop community care in this context, its seems clear that contemporary community care - what is conventionally described as the policy response to the ideologically-driven deinstitutionalisation movement - is not a new trend. It is rather, an attempt to return to a former mode of care within the context of a very different society. In practice, therefore, making this shift has created many challenges, including both the need to jettison the ideology which brought about the institutional era, and the need to re-establish community integration along with a suitable yet supportive role for the wider community, both of which were all but extinct in the institutional era.

In the next chapter, specific consideration is given to how both the concept of community integration and the role of the wider community have developed, and what factors have shaped contemporary ideas about these aspects of community care for adults with intellectual disabilities. This is done in an attempt both to suggest how community care has been "re-conceptualised" for the present day, and to discuss the implications this is likely to have for people with intellectual disabilities and the service providers who support them to live in the community.

[1] The 1913 Mental Deficiency Act and Section 28 of National Health Service Act (1946) also encouraged provision beyond hospitals for people with intellectual disabilities.

[2] For a review of some of this research, see Race, (1995) .

[3] Studies not cited individually in this thesis include: The Social Problems of Mental Deficiency (1956) by O'Connor & Tizard; The Mentally Handicapped and Their Families (1961) by Tizard & Grad; and Community Services for the Mentally Handicapped (1964) by Tizard.

[4] In addition to the Ely Inquiry, there were ten other hospital inquiries. An excellent review of these can be found in Martin (1984).

[5] This excerpt from the PPG Report (1979) is quoted in A Better Life (SHHD & SED, 1979), paragraph 7.24, page 74.

[6] A number of reports discuss these issues, including NDG (1978); DHSS (1980); DHSS (1981a); and DHSS (1981b).

CHAPTER TWO

"Interpreting the Scene from a Community Integration Perspective"

Overview

This chapter is intended to present an analysis of the impact that various factors have had on contemporary understandings of community integration and the role of the wider community in community care for adults with intellectual disabilities. The chapter is made up of two parts: part one analysing the impact of the historical events and policy developments introduced in Chapter One; and part two considering the impact of significant theoretical developments from the field of disability. The chapter concludes with a discussion of how it seems, the varied factors presented appear to have influenced the way in which contemporary service providers have developed community care for people with intellectual disabilities. The implications for this study are then considered.

Introduction

As stated previously, community care is not a new trend. It does however, involve re-establishing community integration for people with intellectual disabilities who have been subjected to almost 300 years of both intentional and consequential segregation. This includes identifying a suitable role for the wider community, whose involvement in the lives of people with intellectual disabilities had been all but extinct in the institutional era.

These very peculiar circumstances have forced those who develop policies or services for people with intellectual disabilities to explicitly define community integration and the wider community's role within this. Community integration would normally be viewed as a state of being, taken for granted by most of us. But for people with intellectual disabilities, it is something that many do not begin with when they enter community-based living. Therefore, community integration becomes a process which can lead them back from years of segregation. Consequently, the need to facilitate community integration is likely to be part of the agenda of those who support people with intellectual disabilities. How this agenda is addressed is of course, dependent in part upon how agencies understand the meaning of community integration, what is involved in achieving it, and how important this is in terms of the overall support given to people with intellectual disabilities. In exploring how contemporary understandings of these issues are likely to have been shaped, a number of factors need to be considered.

Part One: Reflecting on history and policy

The deinstitutionalisation movement: an agenda for closure

Going back to what was probably the earliest factor influencing the way community integration and the role of the wider community are currently viewed, I begin by considering how the deinstitutionalisation movement was likely to have had an impact. It appears, through close analysis, that the movement did not base its philosophical arguments for change on the need to return to the former values of the pre-institutional era, which demonstrated integration and care by the wider community. Therefore, the importance of community integration and the need to stimulate a renewed caring role for the wider community did not emerge as driving forces behind the deinstitutionalisation movement.

Indeed, upon closer inspection, this movement came to acknowledge the importance of community integration in quite a roundabout way. By looking critically at the account of the deinstitutionalisation movement, it seems clear that the movement's objectives were more about closure than commencement: about ending institutionalisation rather than advancing arguments for integration. Historians generally agree that the movement was concerned with remedying three particular issues:

1) the permanent detention of intellectually disabled people in hospitals;

2) the horrific conditions in hospitals; and

3) the denial of rehabilitation and training opportunities available to people with intellectual disabilities who were living in hospitals.

When the Mental Health Act made permanent detention less of an issue, objections turned to focus on the extremely poor physical conditions in hospitals. By suggesting the possibility and indeed desirability of community-based care, the Mental Health Act laid the foundation for those objecting to the living conditions in hospitals to call for community care as an alternative to institutionalisation. However, because the deinstitutionalisation movement evolved as a movement largely concerned with ending institutionalisation, rather than spurring the positive development of community care, the emphasis was largely one of closure, rather than commencement.

There was noticeably less emphasis on elaborating about what would replace institutional care. Therefore, "community care" was initially defined in quite a limited way, as care outside of institutions (Bulmer, 1987). A more positive definition of community care did not exist for people with intellectual disabilities for some years to come. As well, certain factors within the deinstitutionalisation movement seemed to make a recognition of the positive value of community care particularly difficult to focus upon.

The Scandinavian theory of normalisation raises doubt about the necessity of community care

As the deinstitutionalisation movement got under way, and concern turned toward the inhumane physical conditions in large institutions, there is evidence that some theorists were suggesting that these conditions were not necessarily justification for abandoning this model of care. This position undermined the positive value of community-based care. By emphasising the importance of higher quality environments, but failing to say that institutions, by their very nature, could not provide these environments, the early Scandinavian notions of normalisation

implicitly suggested that 'normalisation' could be achieved within institutions (Grunewald, 1974). Despite being concerned with improving the living conditions of people with intellectual disabilities, its failure to whole-heartedly reject the institutional model of care only compounded the lack of positive value associated with community living in the early deinstitutionalisation movement.

Research emphasises the training & rehabilitation potential of people with intellectual disabilities in hospital

Many researchers who had an equally influential voice in the deinstitutionalisation movement also failed to focus directly on the positive value of community living in their arguments for the deinstitutionalisation. First, community care was argued for on the basis that many people with intellectual disabilities didn't need the type of care provided by long-stay hospitals.[1] Care in the community was not viewed as a more positive choice because it was community-based, but rather because it would offer a more *appropriate* level of care.

Second, community care was argued for on the basis that people with intellectual disabilities needed to develop their skills and abilities. Many early researchers argued for community care because people with intellectual disabilities demonstrated the potential to be trained in basic living and self-care skills; yet hospitals had ceased to concern themselves with the rehabilitation or training of those intellectually disabled patients in their care.[2] Community care was once again not a positive choice because it was community-based, but this time because it offered a greater potential for people with intellectual disabilities to improve their skills. This was confirmed by the fact that some researchers argued that those judged to be incapable of rehabilitation should remain in hospital.[3]

In retrospect, the body of research that characterised the deinstitutionalisation movement reflected a positive call for moves away from the institutional model of care, based on its inappropriateness and inadequacy. Community care was preferred because it offered an opportunity to change the balance between supervision and instruction, not because it offered opportunities to end segregation and isolation in favour of integration with the wider population.

Research into the problems of isolation and segregation

Overall, very few researchers who wrote between 1950 and 1970 dealt with issues of social isolation and physical segregation as reasons for pursuing community care. However, arguments asserting the value of community integration and the importance of a wider community are not entirely absent from the research contributions which formed the platform of the deinstitutionalisation movement. One can find concern for problems of isolation and segregation appearing in literature near the very end of the deinstitutionalisation movement, albeit almost twenty years after the movement began.

By the late sixties, there is evidence that researchers had begun to address issues of social isolation. Unfortunately, the first to deal with the issue followed a line similar to that of earlier researchers. Gunzberg (1968) was concerned with the social isolation that people with intellectual disabilities faced; but he responded to this by emphasising the importance of training - this time in social skills - to rectify this isolation. Quite surprisingly, Gunzberg did not suggest that the location, size, and organisational structure through which the training was provided was critical to ending isolation (Race, 1995). Indeed in earlier writings, Gunzberg (1957) described hospitals as appropriate rehabilitation centres. Again, this made

deinstitutionalisation not a movement in favour of the inherent value of community living, but rather a movement focused on the importance of skill acquisition. Like the Scandinavian concept of normalisation, Gunzberg's assertions did not include a clear mandate for community-based services.

Yet it seems a philosophical watershed appeared within the five year period between 1968 and 1972. During this period, a number of influential events occurred which resulted at last, in enough momentum on behalf of people with intellectual disabilities to establish a positive argument for community care. First, in 1969 Pauline Morris published the findings of her influential survey of hospitals in Britain (Morris, 1969). She raised the issue of social isolation in a way that for the first time, emphasised the positive value of community-based care for people with intellectual disabilities. Unlike Gunzberg, Morris presented a clear link between social isolation and the physical location of the hospitals, saying that patients were unable to identify with a local community, while visits from friends and relatives were often greatly restricted.

Then, in 1972, Wolfensberger's principle of normalization appeared. Wolfensberger brought the role of the wider community to the fore by suggesting that not only was there a lack of sympathy for the plight of these people, there was also a very real fear and rejection of this population by wider society. He maintained that these attitudes not only underpinned the earlier choice to segregate and institutionalise large numbers of people with intellectual disabilities, but also continued to exist as a *consequence* of those earlier choices. Wolfensberger argued that the images of these people which were portrayed by institutions only provided rational evidence for that fear and prejudice. Therefore, his principle included a firm rejection of institutions as inhumane and seriously damaging to the reputation that people with

intellectual disabilities had in wider society. But the principle went further than rejecting institutions: it supported the absolute value of community living by arguing that only through integration into wider society could people with intellectual disabilities adopt roles and patterns of living that would make them valued, thereby preventing future discrimination.

The principle's impact in Britain however, resulted in a clouding of this clear focus on community integration and the need to change the attitudes of the wider community. As mentioned in Chapter One, the principle itself did not have as much impact in Britain as PASS, the tool Wolfensberger developed for evaluating services which is based on his normalisation theory (Tyne, 1987). As a consequence it seems, the popular interpretation of normalisation by service providers in Britain over-emphasised the quality of living environments and the importance of encouraging the development of acceptable behaviours & social skills. Therefore, although the principle was an effective advocate for community care, its impact in Britain did not emphasise the importance of integration, beyond the need to utilise ordinary residential accommodation located in existing communities. Those attempting to use the principle as a guide for their work focused on the need to change services, rather than the need to emphasise a role for the wider community which services - no matter how well improved - could never provide. Ultimately, it seems the importance of social integration was not what many professionals took from Wolfensberger's theory.

Conclusion: the movement in perspective

It seems clear that when the 1971 White Paper appeared as the first significant policy statement in Britain which addressed community care for people with

intellectual disabilities, there had been, up to that point, very little emphasis on either the positive value of community integration or the wider community's role in the care of people with intellectual disabilities. The need to rectify the unacceptable conditions of long-stay institutions, and to develop the full potential of people with intellectual disabilities through training and rehabilitation, were the two themes which ran through much of the deinstitutionalisation movement. Community care was hardly a positive choice, given these ideological stances. Although policy-makers began addressing community integration and the wider community's role more directly, they too appeared to struggle with their meaning and relevance to community care.

Community Care Policy

I now move to an analysis of community care policies, considering how community integration and the role of the wider community figured into the pattern of community-based care for which these policies called. Although such an analysis could be quite extensive, I have limited my commentary to those issues which I feel are of central importance to my study. I treat the subjects of community integration and the wider community's role separately, to better enable the reader to see the thematic messages that the body of community care policy is likely to have intimated to service providers.

Concepts of integration

In general, the history of community care policy demonstrates a lack of both clarity and agreement in regard to the concept of community integration. This appears to be the result of two things. First, although an emphasis on integration has featured in every community care policy, the contemporary concept of community integration seems to have evolved from early calls for quite different types of integration. Second, when community integration has been addressed in policy, it is often referred to as a *product* of relocation rather than a *process* which needs to be facilitated and supported by community care services.

The meaning of integration

Support for integration has always been represented in policy by calls to end segregation. Yet what has been called for in response to this consensus on ending segregation has not always been *community* integration. While the Royal Commission report which spawned the Mental Health Act of 1959 was said to have "recommended radical changes with a new emphasis on community care and breaking down segregation" (DHSS, 1971), in actuality, the basis for ending segregation in this report was focused on *the integration of services*, rather than *the integration of people*. The Commission recommended:

> ...that all the general social services should be available to the mentally handicapped as well as others and that mental health services should be fully integrated with other health and welfare services. (DHSS (1971) p. 12)

As well, the Seebohm Report's reference to integration involved the need to promote *administrative integration* of the system of residential care that was to be developed and run by local authorities (Home Office, 1968). Both of these policies were

concerned with ending segregation by promoting service integration, not community integration. This early focus on the integration of services, which emphasised the importance of physical relocation to end the segregation of people with intellectual disabilities, impacted significantly on the way in which other policy-makers have suggested that community integration can be achieved.

Integration: product or process?

Because the early policies mentioned above were largely concerned with changing the physical location of where people with intellectual disabilities lived, it was assumed that physical relocation to local communities would result in people being integrated into *the life of the local community*. Consequently, while the 1971 White Paper offered a clear call to end segregation, it made very limited reference to what would constitute integration for people with intellectual disabilities. Beyond asserting that they should "take part in the life of the local community," what this meant in practice and how it could be facilitated was not addressed. Instead, the Paper's recommendations followed earlier assumptions emphasising physical relocation: they called for people to be placed in residential settings which were "not isolated but in centres of population" (DHSS, 1971).

Policies that followed the 1971 White Paper demonstrated similar stances on community integration. Both the Scottish Blue Book (SHHD, 1972) and the National Development Group Report (1978) supported the view that community integration could be achieved by hospital residents, if hospitals were not remotely located. The authors of the Blue Book maintained that "the barriers between hospital and community are largely geographic," and their recommendations supported the physical relocation of people with intellectual disabilities as the way

to end segregation (para. 7.31). What might be required beyond this was not discussed.

A Better Life, published seven years after the Blue Book, continued to support the paramountcy of place, saying that the use of ordinary housing would promote community integration (SHHD, 1979, 6.37). The Jay Report (Jay, 1979), while being heavily supportive of community integration, followed the traditional focus upon physical relocation and the integration of services. The model of care advocated by Jay was firmly committed to the use of ordinary housing and generic, local community services as ways to promote integration.

In *Caring for People*, (DoH, 1989) the focus of the recommendations for people with intellectual disabilities in Scotland continued to be on relocating these people from long-stay hospitals to community-based residences. Similar to the policies that had gone before, beyond the mere physical placement of these individuals within local communities, little was said about what the objectives for community integration should be beyond relocation, implying again that relocation would achieve integration. *Caring for People* only reiterated what has been said over and over in previous policy: "the government's policy is to...provide opportunities for people with a mental handicap to join in the life of the community to the fullest possible extent" (p. 84). How this objective could be translated into strategies for new service development continued to remain unclear.

The problem of isolation

Despite the overwhelming emphasis on ending physical segregation in community care policies, there is limited evidence in these which does suggest that policy-makers were aware of the need to address social isolation as something distinct from physical segregation. For example, it seems the authors of the 1971 White Paper were not totally guided by the popular assumption about the relationship between physical integration and social integration. More than twenty-five years ago, their report demonstrated some awareness of the now readily accepted fact that simply living in a local community does not cause a person with intellectual disabilities to become integrated into the life of that community.

In addition, the 1971 White Paper gives some attention to the problem of isolation that people with intellectual disabilities face. This problem was not said to be limited to those experiencing physical segregation in institutions. The authors recognised that even small, community-based houses can breed isolation.

> A small hospital unit or residential home can be as isolated as a large one if it has no visitors. (DHSS, 1971, p. 58)

In addition, it was acknowledged that the problem of isolation was also an issue for those living with their parents in local communities.

> Even among those who lived at home, many...were hidden away by their families, and few mixed socially. (DHSS, 1971, p. 3,9)

This statement makes it clear that social isolation was viewed by policy-makers as a significant problem for *most all* adults with intellectual disabilities, regardless of where or with whom they lived. Consequently, the Paper appeared to recognise that the viability of effective informal support networks for the large majority of people

with intellectual disabilities was extremely limited. It is less clear whether they recognised that simple relocation was likely do little to change this. Despite these two excerpts which suggest an understanding of the challenges involved in bringing about community integration for people with intellectual disabilities, this subject was by no means given prominence in the overall policy statement. And in terms of finding proposed solutions for this, similar to those the Paper laid out on the subject of physical segregation, these are largely non-existent. Consequently, what practitioners took from this White Paper was an agenda for physical relocation.

Meanwhile, the Jay Report (Jay, 1979) also appeared to avoid making the assumption that physical integration would automatically lead to social integration.

> **Whilst physical integration of accommodation for mentally handicapped people with the building in which other people live will in no way guarantee the acceptance of mentally handicapped people, it will, we believe, provide a first step to fuller social integration. (para. 135)**

By describing physical relocation as a first step to social integration, the Jay Report portrayed community integration as a *process* which *begins* with physical relocation, rather than a *product* which *results* from this relocation. Ultimately, as policy-makers paid increasing attention to the problems of isolation and the distinction between physical and social integration, the role of the wider community in community care became increasingly relevant. As time passed, it was seen as more central to the success of community care generally. Integration was not only seen as a process, but it seems, as a socially constructed process. But these discussions represent mere 'asides' to the primary messages being conveyed through the overall collection of community care policies which were being developed. This was particularly the case in Scotland for reasons that Chapter One makes obvious.

Conceptions of the wider community's role

Overall, one can find support in principle for the wider community's involvement in community care for people with intellectual disabilities in the content of the various policies. However, the content of these policies also reveals some critical assumptions and recommendations that have inhibited the extent to which the wider community's involvement has become an integral part of the development of community care for people with intellectual disabilities. This section addresses both the evidence of support and those things which undermined these expressions of support.

The seventies yields a clear and supportive vision

The Seebohm Report (Home Office, 1968) is most remembered for presenting the then somewhat radical idea that the wider community's involvement in social welfare would be critical to its success.

> We are not suggesting that 'welfare through community' is an alternative to the social services, but that it is complementary and inextricably woven... The notion of a community implies the existence of a network of reciprocal social relationships, which among other things ensure mutual aid... (p. 149, 147)

The 1971 White Paper went on to translate Seebohm's general support for informal welfare into specific support for these networks in the lives of people with intellectual disabilities, saying:

> Understanding and help from friends and neighbours and from the community at large are needed to...give the handicapped (family) member as nearly normal a life as his handicap or handicaps permit. (para 40-xv)

In addition, the 1971 Paper mentioned the unique value of voluntary assistance which went beyond the need to compensate for inadequate services.

> Neighbours and voluntary groups can offer personal assistance which is valued and valuable simply because it is voluntary - freely offered, not in the course of paid employment, but as a simple expression of personal concern between one human being and another. (p. 57)

What's more, there was a clear argument for the value of one particular form of informal support - friendship - which needed to be maintained regardless of whether people were living in hospitals or community residences.

> At least a third of the patients who now live in hospital are never visited. To befriend an individual patient is one of the most worthwhile forms of voluntary service...When hospital services are reorganised into smaller units, as foreshadowed...voluntary help in maintaining contact with the surrounding community will still be essential. (p. 59,58)

The NDG Report (1978) also emphasised the importance of voluntary efforts being encouraged across a number of areas, and assistance through these efforts being provided in a number of ways. The report also made clear the importance of a variety of relationships for people with intellectual disabilities who lived in hospital (para. 4.1.2, 4.1.6, 4.1.7). The report went on to outline the variety of ways that individuals, organisations, and even community businesses could contribute to the support of people with intellectual disabilities.

Likewise, the Jay Report recognised that adulthood presents a new set of challenges to the disabled person, his/her family, and society as a whole, and stated that "the community...must assume a far greater responsibility than at present" (1979, p. 128). As well, the report stated that success would be dependent upon "professional staff, the community, and society as a whole accepting and committing themselves to a very different pattern of services and a very different role in society for the

handicapped person" (p. 95). This position clearly re-established Seebohm's view that successful community care would require a balance between formal and informal welfare and support.

The eighties brings a narrow focus on role

Initially, the eighties did build on the Jay Report and began with some positive statements on the need to develop informal networks of support. The Barclay Report (NISW, 1982) supported Seebohm's general emphasis upon the importance of community in social welfare. Barclay defined community as a network of informal relationships between people connected with each other, and described the strength of community as the potential of these networks to "mobilise individual and collective responses to adversity" (Bulmer, 1987). *People who are mentally incapacitated* were one group that Barclay said the informal networks of community should respond to.

However, as a result of the political trends of the late eighties, there was a significant shift in the focus of community care policy. The positions of Jay and Barclay seemed to get lost in policies and legislation which were focused solely on mobilising *existing* informal support networks, rather than recognising how and why they should be developed where they did not exist. The strategic legislation of the eighties talked at length about informal support, but only in terms of existing networks which could offer care in order to avoid the segregation of those already integrated. This focus, largely meant to address the needs of elderly people, diminished the role that the wider community was expected to have in the lives of people with intellectual disabilities moving out of institutions.

Who's supplanting who?: the shift in emphasis from the seventies to the eighties

Overall, the visions of the wider community's role in relation to professionals appear distinctly contradictory across the policies of the seventies and eighties. Policies of the seventies emphasised the importance of voluntary efforts not supplanting professionals while the policies of the eighties landed firmly on the side of professionals not supplanting informal support networks. Barclay asserted this position very strongly, defining the role and tasks of social workers as mobilising and sustaining existing informal networks. Griffiths (1988) followed a similar line, defining the main aim of social work as supporting existing caring arrangements, and enhancing rather than supplanting these by augmenting them with the proper balance of formal services. The importance of this task became Griffiths' platform for the introduction of care management to social work.

Given this shift in emphasis toward the paramountcy of informal support, one might logically expect that policies of the eighties would have significantly affected the degree to which service providers for people with intellectual disabilities began to focus on the importance of informal support networks. In reality, the opposite appears to have been true. This was partly due to the fact that these policies' position on the role of informal support has proven irrelevant to the majority of adults with intellectual disabilities in Britain, especially those who have moved out of long-stay hospitals.

All policies which have appeared since 1980 have been based on the assumption that informal carers provide the bulk of community-based care. And while Griffiths recommended arranging "the delivery of packages of care to individuals, building first on the available contributions of informal carers and neighbourhood support"

(1988, p. 1), it seems neighbourhood support for people with intellectual disabilities has hardly been tackled. Informal carers are now the cornerstones of community care; but for people without existing informal carers, community care has evolved as a wholly professional endeavour, hardly different from institutional models.

Despite the overwhelming emphasis on informal carers in recent policies, comparatively little has been said about how informal networks should be encouraged for people who don't have them. For instance, although Barclay mentions the importance of developing networks where they don't already exist, it is done very briefly, and without giving practical guidance of how to do this :

> The director of social services or the head of a voluntary agency must be concerned with discovering, and where necessary establishing, networks for the whole geographical area or client group for whose social care he has responsibility. (NISW, 1982, p. 33; emphasis added)

Although Bulmer (1987) concluded that the Barclay Report "stands as an important statement about the character of community care in the late twentieth century," it and the other significant policies of the eighties have had little relevance for the thousands of people with intellectual disabilities who have and continue to experience social isolation, either in local communities or in long-stay hospitals.

Conclusion: policy in perspective

By discussing informal support networks only in terms of existing networks, these recommendations for community care development leave out a role for informal support networks where they do not already exist. Consequently, they also leave out a role for services in stimulating the development of these *potential* networks. For the thousands of people with intellectual disabilities who lacked these networks,

community care has evolved as an entirely service-oriented process, initially limited to achieving relocation to community-based accommodation. Other factors however, have also influenced the way in which contemporary service providers view community integration and the wider community's role in the development of community care for people with intellectual disabilities. These factors have evolved from within the field of disability itself.

Part Two: Developments in the disability field

Introduction

In addition to the mixed views which have been expressed in policy about community integration and the role of informal sources of support for people with intellectual disabilities, it seems an ideological divide on these issues has developed within the disability field. A number of contributors to the field have presented views which either directly or indirectly address these issues. What I argue here is that the collective impact of these views is likely to have left modern day community care providers somewhat unclear about the real value and legitimacy of promoting community integration and facilitating informal support networks for people with intellectual disabilities. Therefore, these factors require consideration.

In favour of community integration

Arguments for encouraging community integration and the development of informal sources of support in the lives of people with intellectual disabilities have come from a variety of sources. First, there has been a growing debate over the legitimacy of the concept of least-restrictive environment (LRE). This principle, described as "a continuum of residential and vocational programmes that reflects an ordered sequence of placements that vary according to the degree of restrictiveness," has been criticised for falling short of supporting total integration for adults with intellectual disabilities (Taylor, 1988, p. 172). Some involved in the debate have argued for the adoption of *a concept of full integration* which would subsume the principle of LRE within a framework reflective of more person-centred values. {See Appendix, p. 433 for a summary of the concept of full integration.}

Support for the values underpinning this concept grew during the eighties, as the result of three critical, ideological contributions to the field. First, the appearance in 1983 of a revised version of the principle of normalization, which Wolfensberger called *Social Role Valorisation*, focused more centrally on the importance of people with intellectual disabilities gaining access to socially valued roles and opportunities to participate in wider society (Wolfensberger, 1983). Then, John O'Brien's introduction of the *Five Accomplishments* in 1987 made re-focusing on the whole person and the breadth of their life experience an important aspect of planning effective community-based services (O'Brien, 1987). Two of the five accomplishments said to be critically important in people's lives deal with an individual's relationships (community participation) and the extent of his/her involvement in the wider community's places and activities (community presence). Through this focus, the accomplishments framework has been instrumental in

advancing both community integration, and the involvement of the wider community in the lives of people with intellectual disabilities, as service principles for community care.

Finally, in 1988, the 'Ordinary Life' campaign began in Britain, focusing on the *ties and connections* of people with intellectual disabilities as central aspects of successful community living. The campaign emphasised the fact (which was becoming increasingly obvious in practice) that being *in* a community was not necessarily being *of* that community (Kings Fund, 1988). All of these developments legitimised the importance of community integration and the wider community's role in making community care for people with intellectual disabilities a success. However, more recent developments have cast doubt on these perspectives, creating an ideological split for service-providers to grapple with.

Questioning integration & the wider community's role

In contrast to the above groundswell of support within the field, for the importance of community integration and the wider community's role in this, some recent writings have raised serious concerns about the positive value of promoting a concept of full integration.

Research contributions

Szivos (1992) argues that there are limits to how positive integration can be for adults with intellectual disabilities. Szivos is critical of the way in which a focus on integration has forced people with intellectual disabilities to *go it alone* in integrated

settings and activities. While Szivos agrees that such wide dispersal of people in communities may reduce the visibility of their disabilities in line with the goals of normalisation, she argues that this approach may also damage the intellectually disabled person: she reports that these people have experienced anxiety, harassment and rejection as a result (p. 120-1). In particular, she believes people with intellectual disabilities may experience a loss of self-esteem due to the stigma they face in attempting to form relationships with non-disabled peers. Szivos bases her argument on social comparison theory (Festinger, 1954), concluding that:

> ...people with disabilities in an integrated setting may find themselves in a situation in which a large proportion of the social comparisons they make will merely serve to confirm in them a sense of inferiority. (p. 121)

In addition, Szivos suggests that an emphasis on integration may result in people with intellectual disabilities having restricted opportunities to form friendships within their own group and consequently, to form allegiances based on solidarity. Szivos is critical of both Wolfensberger and O'Brien, whom she claims support the notion that interaction with non-disabled people is a more important goal than interaction with disabled people. She concludes by arguing for the creation of a group identity based on solidarity rather than dispersal, which is similar to other social movements. Yet although Szivos maintains hers is not an argument for "returning to the ghettoisation of the institutional era," but rather for "moving to a climate in which account can be taken of people's needs and desires for affiliation," her position shares some parallels with the arguments of Nils Christie, who writes *in defence of the ghetto* on this subject.

Christie (1992) argues that people with intellectual disabilities "choose each other as the only available, long-term, interactional partners;" yet service providers do not support this, "but instead spread (them)...out so as not to create a ghetto" (p. 158).

Out of a study of Camphill communities, Christie puts forward what he calls "powerful arguments in favour of the ghetto." Like Szivos, Christie argues that in the process of placing people in communities:

> ...we should ensure that they live close together, that they can reach each other all the time and meet each other as if they were living in a ghetto. (p. 158)

Christie concludes that people with intellectual disabilities should not be denied the right to form a ghetto of sorts, which includes all the benefits of solidarity and community that come with these social arrangements (p. 159).

These philosophical stances, although not absolute arguments against community integration and interaction with the wider community, raise questions about pressing forward with a concept of full integration. In addition, it seems these and similar arguments have indirectly renewed support for the establishment of *separate* communities like those of Camphill and L'Arche. In these artificially maintained communities, people's quality of life is said to be maximised because of the atmosphere of total acceptance that is fostered.[4] Whether these communities actually achieve such utopian qualities is a subject for on-going debate. However, while testifying to the benefits of people with and without disabilities living together, the separatist nature of these communities (illustrated by the fact that very few people know of their existence or understand their philosophy) does seem to suggest they are underpinned by an assumption that 'ordinary' communities are not the most desirable places for people with intellectual disabilities to live.

Rights movements and the wider community's role

Beyond the concerns expressed in the recent literature of the field, the wider disability movement also appears to present an agenda that mitigates against focusing on the facilitation of relationships and involvement with the wider community. While the field of intellectual disability has been dominated by normalisation (which in part has underpinned recent moves to adopt a concept of full integration), the wider disability movement has just begun to address the relevance of normalisation to its ideology.

Two disability activists, Morris (1993) and French (1993), have recently considered normalisation and rejected it, questioning whether disabled people actually want to be 'normal.' In contrast, writers of the disability movement and the intellectual disabilities field have now begun to reverse the thinking process by questioning whether the social model of disability (the philosophical cornerstone of the disability movement) is relevant to people with intellectual disabilities. Walmsley (1994) points out that the social model, which puts the onus on society to change, stands in sharp contrast to normalisation, which puts the onus on disabled people to change. She also agrees with Szivos and Christie about both the need for social movements based on solidarity, and the fact that normalisation works against this by asserting that the most valued relationships are with non-disabled people. She contends that normalisation may not just inhibit progress, but may actually reverse it because:

> ...the use of culturally valued means to produce culturally valued ends as advocated by Wolfensberger may actually reproduce discrimination on the grounds of gender, race, sexual orientation, age, etc. (p. 150)

While these common criticisms of normalisation are not a rejection of the value of community integration, they are a cautious call for integration and involvement with the wider community to be achieved on disabled people's terms. Walmsley argues in support of self-advocacy groups as promising evidence of a movement based on solidarity and social change taking shape for people with intellectual disabilities. In some ways, the disability movement's belief that this is the most hopeful avenue to their primary goal of liberation, necessarily emphasises the fact that relationships among disabled people are paramount, thereby setting its agenda in contrast to that of full integration.

Models of community living define the wider community's role

Growing out of the disability movement discussed in the previous section, the independent living movement is gaining increasing recognition as an inspiration for community-based service development. It's values have long been important in services for physically disabled people, but are now increasingly being considered in service development for people with intellectual disabilities. Although the independent living movement has its roots in deinstitutionalisation, it has been largely focused on the *physical* barriers to independent living. Consequently, the movement has largely failed to address the barriers people with intellectual disabilities face in the battle for independent living options. Nonetheless, the movement has broadly identified two areas for change: the need for personal assistance which enables a disabled person without creating dependency; and the need for financial resources to be channelled directly to the disabled person in order that he/she can control the arrangements for personal assistance.

Although early projects utilised informal support from neighbours (Davis, 1981), the movement now takes the view that:

> ...using friends or relatives as unpaid carers means that the disabled person is unlikely to be able to play an equal role in personal relationships or to participate fully in society." (Morris, 1993, p. 27)

The logical conclusion reached is that "the emphasis on informal care, which is at the heart of community care policy, is in direct conflict with the principles of independent living" (Morris, 1993, p. 27-8).

The fact that informal carers may often cause those they care for to become dependent on them is hardly disputable. Although options other than those which create dependency have not been available, the problem does not in my view seem to be about the informal aspect of this arrangement. It is rather, two-fold. First, it is the totality of the caring arrangement, rather than *who* is doing the caring, that appears to create the dependency. Whether it be an unpaid carer or a paid provider, the fact that either provides *all* of the assistance that someone requires creates a situation of dependency that any *all-or-nothing* model would bring. Therefore, dependency can happen in formal or informal care, not because the *source* of the care is necessarily wrong for the person, but because there is a problem with the *balance* of care. This conclusion appears to be justified by what is happening in practice: where the balance is tipped to formal, paid care, like in the intellectual disability field, one can see an emphasis on facilitating informal sources of support to rectify the balance; while where the opposite is true, we see an emphasis on developing formal, paid options of care - again to rectify the balance.

Second, the whole notion of *care*, used by policy-makers in lieu of the term *assistance*, is likely to imply that the person being cared for is incapable of having

any role in this process. Thus, the term care seems to create an atmosphere where dependency is likely to develop, regardless of whether 'carers' are informal or formal, paid or unpaid.

In the end, it seems the issue is not *who* provides the support, but how much of a monopoly provider they are. If the presence of a monopoly does not lend itself to promoting choice and quality in market terms, why should it be expected to do so for individuals, in lifestyle terms? Secondly, the issue is also whether 'carers' view the support they provide as care or assistance: whether they see themselves as sustaining or enabling a person. These two issues are the sources of tension between fostering independent living and fostering informal support networks. Yet on the surface, few recognise these implicit themes. What is conveyed by the independent living movement is that paid assistance is preferable to informal, freely given assistance, and that relying on informal support is both dis-empowering and charity-evoking for disabled people.

Within the field of intellectual disability however, a "middle ground" has developed through the *supported living movement*. Peter Kinsella (1993) has been the key writer on this subject in the UK. Supported living has evolved in response to the recognition that group homes have not lessened the dependency that people with intellectual disabilities typically have on formal, paid support (Emerson & Hatton, 1994). Sinson's study (1993) on microinstitutionalisation confirmed this, and concluded that group homes are not achieving the radical improvements expected. The supported living movement has therefore been characterised by its central focus on the empowerment of people with intellectual disabilities and its radically individualistic model of community living (Emerson & Hatton, 1994). The success of the approach is based on the supporters having a deep personal commitment to

the individual, while informal sources of support are also considered a fundamental ingredient.

This theory has many similarities with the concept of life sharing, first introduced by Wolfensberger in 1975 with regard to the field of mental health. Schwartz (1992) describes this arrangement as emerging from a relationship brought together through citizen advocacy. Lifesharing involves supportive living arrangements where people with and without disabilities live together, without remuneration to anyone involved (Wolfensberger, 1975a). Housing co-operatives have often become the practical reality spawned from the life-sharing concept. These models make informal support from the wider community preferable and indeed essential to successful community living, while holding firm to the values of empowerment and a personalised approach.

The debate over a caring community

All of these somewhat polarised developments in the field revolve around one central question: is the wider community, and indeed wider society, a caring one for people with intellectual disabilities? O'Brien seems to say yes, without stipulation. Wolfensberger says yes, if you play by society's rules. The independent living movement says yes, if you can change society's attitudes and join them on your own terms. Szivos, Christie, and those supporting *separate* communities seem more dubious about the presence of a caring community.

Two final developments seem important to raise here which together emphasis the breadth of opinion on this subject. First, one can observe a growing movement

under the banner of 'inclusion' currently sweeping both Britain and North America. Inclusion has come to represent full integration - not just physical integration but full social integration. A central theme of inclusion, or the marker which signifies that it has been achieved, is the provision of informal support, both social and practical. 'Natural supports,' created by the evolution of the wider community's role from embracing to enabling, represent an alternative to both professional support and the concept of informal care which has been advanced in recent social policy. Natural supports address far more than basic care; where they are supported to exist, they enable inclusion in education, employment, and community life. The movement to develop natural supports has been based on the firm belief in the existence of a caring community, and on what Nisbet (1992) describes as "an emerging understanding of the capacity of typical communities to support individuals with complex needs" (p. ix).

Second, and in sharp contrast to the inclusion movement, one can see the rise of a contemporary eugenics movement. Stanworth (1989) identifies the 'new eugenics' as the modern day use of reproductive technologies as a vehicle for genetic engineering (p. 91). This would eradicate the unfit from the population, not by extermination, but by eliminating what medical and political lobbies see as 'problematic' genes, and replacing them with what these groups see as 'meritorious' ones (Kelves, 1986). Rather than asking either society or people with intellectual disabilities to change, scientific manipulation of pregnancy (and pregnant mothers) will make this unnecessary. Underlying this basic desire to pursue perfection is of course, concerns for the public purse and the opportunity to save money by engineering a reduction in those people who might need to depend on public assistance. The implicit message in this is that people with intellectual disabilities are inferior, and steps should be taken to prevent these people from continuing to

exist as one strand of our diverse population. Therefore, money should be spent - not on programmes to support these people - but on programmes to prevent more of these people from being born (Stanworth, 1989). At its starkest, this is perhaps the community which many fear involving in the support of people with intellectual disabilities.

In retrospect

One is struck initially, by the extremes of viewpoints expressed about both the wider community and the legitimacy of community integration in the above review of perspectives from the field of disability. How could scholars considering the same world and the same issues come to such dramatically opposing points of view? The range of opinion, both about people with intellectual disabilities and their prospects for full integration, collectively offers *no clear statement for or against community integration as a principle for service.* Although the most significant theoretical contributions to the field acknowledge the importance of community integration, the concerns and criticisms raised about the assumptions on which support for community integration has been based, cannot be ignored.

Chapter Conclusion

In this chapter, it has been shown that a range of factors relating to history, policy and theoretical debates within the field are all likely to have impacted upon the views taken by service providers about the importance of community integration

and the wider community's role in this. In considering the services which have developed for people with intellectual disabilities, the parallels that exist between the discussion presented in this chapter and the reality of current services seem clear.

The deinstitutionalisation movement's consistent lack of vision about what community care should look like in practice was likely to have been influential in the findings of research studies which demonstrate that institutional practices and lifestyles have survived despite relocation to smaller, community-based living options (e.g. Sinson, 1993). In some ways, this suggests that the pattern and focus of support offered through community care has hardly changed from that offered in institutions, although community care is generally agreed to be a decidedly improved version of the former. As well, the deinstitutionalisation movement's emphasis on the training and rehabilitation potential of people with intellectual disabilities has resulted in these areas becoming the focus for community residential programmes (Tyne, 1987). These circumstances explain in part why recent research evidence (presented in the next chapter) suggests that community involvement and relationships have been neglected. One can still see the focus on training today, where lessening dependence is thought to be achieved through skill acquisition - teaching people to do it themselves - rather than through fostering interdependence which enables people to get support from a variety of sources to manage life. Where people have not been able to learn to do things themselves, they remain largely dependent on their primary carer, whether it be a paid staff team or a relative.

In addition, normalisation and community care policy has placed significant emphasis on the quality of living environments and the importance of physical

relocation to local communities. Consequently, community care has emulated these values, and much effort has been exerted to place people in community-based residential accommodation which is home-like and comfortable. *Pride of place* has dominated the agenda, and notion of "joining the life of the local community" which appeared in a number of policy statements, has never got further in practice than the use of generic, locally-based services, as very early definitions of integration had suggested. In this context, people with intellectual disabilities continue to be viewed as service-users rather than community members or citizens. As a result, the pattern of people's lives seems to have changed little: with the exception of where they live, they continue to do many of the same things with the same people.

The wider community's role has gone from *supporting* the work of professionals in long-stay hospitals to *doing* this work in communities. The role has been either superficially charitable or wholly responsible. The balance that early policy-makers called for was not entertained by policy-makers of the late eighties. Consequently, encouraging informal support has not meant increasing the variety and amount of support to which people with intellectual disabilities have access. Rather, it has meant where possible, eradicating the need for paid staff by narrowing the wider community's role to that of full-time carer. For the thousands of intellectually disabled people who were previously isolated from communities by institutionalisation, the prospects for informal support are limited. Unfortunately, because policy-makers have not emphasised the need to develop *potential* networks, and service providers have been preoccupied with teaching independent living skills, social isolation continues for many people with intellectual disabilities.

Yet although the field has long been concerned with rectifying isolation, opinions have developed more recently that mitigate against an emphasis on full integration.

The debate over the potential of a caring community has caused some to conclude that separate communities for intellectually disabled people represent the best lifestyle opportunity. Others argue that facilitating relationships between people with intellectual disabilities and the wider community is not as important as facilitating the development of a social movement among intellectually disabled people. Still others contend that relationships with the wider community can cause great harm to the self-esteem of people with intellectual disabilities, and they maintain that service providers should exercise caution in facilitating such relationships.

Implications for service providers

The collective impact of these factors appears to have left service providers working with a model of community care that does not prioritise community integration, or the involvement of the wider community in the lives of those being supported. In addition, where providers *are* tackling community integration, to a large extent they are doing so without a knowledge base which either firmly justifies the validity of pursuing community integration or suggests tested strategies for doing this kind of work. Negative views about wider society, and the capacity of people with intellectual disabilities to have and enjoy relationships with non-disabled people, give credence to service providers who either claim to have tried and failed, or resist trying at all, in the area of community integration. In addition, anti-government sentiments have caused some to view the promotion of informal networks as a ploy to save the government money and absolve them of their ultimate responsibility for social welfare. To a large extent, the jury is still out on both community integration and the wider community's role in this process.

Implications for this study

Part of this study is concerned with whether or not a caring community exists. But beyond this, in some ways it is more important to be concerned with what service providers think about this issue, and how their views affect the way they develop and deliver support to people with intellectual disabilities. Given the very mixed positions that have been taken by policy-makers and writers in the field of disability, it must be accepted that *service providers as a group will be likely to share no firm stance on community integration.* They will be influenced by all of the factors considered in this chapter, and others which may not have come to light yet through the literature. Therefore any study of community integration must continue to acknowledge and advance the debate over the legitimacy of this principle for service. The debate can be advanced not just through theory, but also by evaluations of practice outcomes. In particular, evaluations of the experiences of people with intellectual disabilities, who now live in local communities as a result of the government's commitment to community care, offer a critical contribution to the debate over community integration. Some work has already been done in this area of evaluation, but it represents the tip of the iceberg in many ways. Still, the cumulative findings thus far are important to consider in planning a research study that intends to move the field further along in the debate on this subject. The next chapter reviews and analyses the findings of evaluative research which has looked at the status of community integration in the lives of people with intellectual disabilities.

[1] See for example Tizard & O'Connor (1952); O'Connor & Tizard (1954).

[2] For example, Kingsley & Hyde (1945); Hartzler (1951); Hiatt (1951); Tizard & O'Connor (1952); Gunzberg (1968); Bavin (1970).

[3] For example, Dutton (1963); Galloway & Garratt (1964).

[4] For a discussion of Camphill communities, see Hailey (1992); for a discussion of L'Arche philosophy, see Vanier (1979).

CHAPTER THREE

"Community Integration: Outcomes and Suggested Explanations"

Overview

This chapter reviews a range of evaluative studies and some more philosophical writings which address the community integration experiences of people with intellectual disabilities. In part one of this chapter, the nature and extent of community integration that research reveals people with intellectual disabilities typically achieve is discussed. In part two of this chapter, the range of explanations for these outcomes, offered by the body of literature on this subject, is reviewed. In particular, evidence of the role of staff in determining the community integration experiences of those they support is considered, and through this, ultimately offered as the primary basis upon which the research study discussed in this thesis was devised.

Part One: Research findings on community integration outcomes

Introduction

As policy is increasingly being translated into practice, observers of community care are turning their interests toward assessing outcomes. Eight years ago, Booth (*et al.* 1990) recognised that while it was well documented that relocations of people with intellectual disabilities from institutions to communities were occurring in greater numbers than ever before, what was less well understood was the implications of this for those who were being relocated. Indeed, many of the major dilemmas which require the attention of researchers lie in the implementation of community care: in determining whether the policy is good for people with intellectual disabilities; to an increasing extent, whether it is cost effective; and to a lesser extent, whether it is good for the communities where intellectually disabled people reside. Although the intention of this part of the chapter is to look at community integration outcomes, it is important to begin by acknowledging that this perspective has not always been a popular theme for evaluation.

Although the preceding chapter clearly indicates that there was some connection between community care policy and support for community integration, this aspect of the policy agenda has not often been given serious attention, either by researchers or service providers. This is not to say that there has not been a significant amount of interest in evaluating community care practice generally. Indeed, evaluative research on community care has developed into a significant field of its own, which has attracted researchers from a variety of disciplines. Yet evidence suggests that perspectives other than community integration have been most popular.

The history of evaluative research on community care

Early researchers in community care, like service providers it seems, were largely concerned with the issues raised by the deinstitutionalisation movement. At its most basic, the success of community care was judged by simple readmission rates, and there is evidence that this continued to be a legitimate perspective until the mid-eighties, particularly for people with challenging behaviour (KFC, 1991). Yet researchers soon recognised the need for a reformulation of the concept of "success" which would focus more on positive adaptation factors (Crawford *et al.* 1979). Gains in adaptive behaviour, reminiscent of deinstitutionalisation arguments, soon became the primary perspective for evaluating the success of community care for people with intellectual disabilities. A significant review of British research undertaken by Emerson and Hatton (1994), which considered over seventy-one evaluative studies of community care conducted between 1980 and 1993, found that studies focusing on competence issues accounted for nearly 40% of those reviewed.

Many studies on adaptive behaviour have concluded that the move from an institution to a community setting encourages gains in adaptive behaviour.[1] However, some findings suggest that initial gains are not always sustained and additional gains over the longer term are less likely to accrue (Cambridge *et al.* 1993). Still, positive changes in adaptive behaviour continue to be considered significant indicators of the success of community care (Booth *et al.* 1990). Another evaluative approach that has enjoyed considerable popularity among researchers in this field is the study of transition effects. Transition has been consistently recognised as a difficult experience for anyone leaving an institutional setting. Transition has been associated with increasing levels of anti-social and disruptive behaviour following relocation (Cohen *et al.* 1977); and for some

individuals, it seems that deterioration in skills and behaviour associated with transition may be more permanent (Martindale & Kilby, 1982). For this reason, the effects of transition continue to be a valued choice of perspective for research.

As calls for increasingly holistic evaluations of success arose in response to the narrow nature of early evaluative perspectives, quality of life studies have grown in popularity. While Wolfensberger (1994) argues that the phrase has been defined in so many ways that its use has become more confusing than illuminating, this perspective has nonetheless been extremely popular. This is evidenced not just by the number of studies which focus on quality of life, but also by the number of scales and similar instruments that have been devised by researchers in attempts to measure success from this perspective.

More recently, as wider quality-of-life studies have begun to consider community integration as part of their evaluations, this perspective has become increasingly popular in evaluating community care for people with intellectual disabilities. And while it is clear that the range of community care projects that have developed are characterised by noticeably dichotomous agendas and goals (Allen, 1988), the literature does suggest some consistent perspectives for inquiry that have been used in studies of community integration. These perspectives rest on the same assumptions about community integration which have been expressed in social policy.

Chapter Two revealed that, at its most intuitive, policy emphasised three critical issues related to community integration. First, there was a recognition of the important distinction between the tasks of ending segregation and ending isolation. Second, it has been acknowledged that social isolation is not a condition limited to

those who experience physical segregation, although it may be more likely to exist and be more extreme for people whose place of residence is physically segregated. Third, it has been assumed, though only in the Jay Committee Report, that community integration is a process, not a product, of community care, which starts with ending physical segregation and moves to ending social isolation (Jay, 1979). It must be remembered that these recognitions, while insightful, occupied only minor parts of the bulk of community care policy. Consequently, the development of actual practice has not always begun with these assumptions at the fore. However, the basic contention that community integration involves both ending physical segregation *and* social isolation appears to have influenced the perspectives taken by researchers thus far.

In light of this, the body of research on community integration outcomes for adults with intellectual disabilities, which is reviewed here, is considered from these two perspectives: I consider the extent to which community integration is being achieved first, through ending physical segregation; and second, through rectifying social isolation.

Findings on the task of ending physical segregation

According to Emerson & Hatton (1994), "the presence of people in community settings and their participation in community-based activities is often seen as the foundation for their true social integration" (p. 22). Early studies reflected these assumptions, focusing on the measurement of physical presence as an indicator of community integration. Yet one critical limitation which typified these studies was their focus on comparing the experiences of people with intellectual disabilities who

live in community-based settings with those of people with intellectual disabilities living in institutional settings. Although the results of these studies are indeed valuable, Emerson and Hatton (1994) are critical of this approach, saying:

> ...if the aim of our service is to enable users to experience a quality of life commensurate with the rest of society, then comparing... hospitals with...small scale domestic housing is simply asking the wrong question...(many studies) have failed to provide comparisons between the quality of life of people with learning disabilities and the general population. (p. 12-13)

No study, except for the Israeli study conducted by Reiter and Levi (1980), has compared the level and pattern of involvement in community-based activities and use of community facilities for people with intellectual disabilities to those of other community members. Therefore, existing studies only allow one to gain a sense of how much *better off* people with intellectual disabilities are, in terms of physical integration, as the result of living in community-based residences rather than institutional residences.

From this perspective, some early studies demonstrated that people experienced improved presence in the community once they had moved from an institutional setting to a community-based residence (Evans *et al.* 1987), and this was interpreted as a hopeful indicator of community integration. Evidence from the studies reviewed by Emerson and Hatton (1994) suggests that this improved presence meant both using a greater variety of community facilities as well as using them comparatively more often than people living in institutional settings (p. 22). Booth (*et al.* 1991) found in a transition study of movers from institutional settings, that there was a greater use of ordinary public services and facilities, reflecting a move away from segregated facilities, segregated sessions within integrated facilities, and services provided within people's residences (p. 101).

On the whole, most transition studies have been positive about community presence outcomes. Yet these studies have been deficient, not only because they fail to compare the experiences of people with intellectual disabilities to those of wider community members, but also because they fail to demonstrate the more long-term impact of community care on people with intellectual disabilities who move from institutions. Emerson and Hatton (1994) point out that the lack of longer-term longitudinal studies makes it difficult to assess these issues, as well as the continuity of service support and the security of relationships between service users and staff.

Where longer-term studies have been done about community presence, there is little evidence that progress beyond that made during the transition period will continue (Bell & Schoenrock, 1981; Birenbaum & Re, 1979). While one more recent study by Lowe & de Paiva (1990) did find sustained increases in the use of community facilities over a five year period; in contrast, Emerson & Hatton concluded, in their review of over 70 evaluative studies, that:

> ...there is little evidence to suggest that *within* community-based services, users are developing new competencies, new relationships, or extending the extent of their participation in their surrounding community. (1994, p. iii, emphasis added)

Beyond concerns over the *extent* of these positive findings, it's also the case that a portion of the transition-based studies of community presence have not actually generated positive findings. It seems that for some people with intellectual disabilities, community presence has not been achieved as the result of living in a community-based residence. While a study by Raynes (*et al.* 1987) demonstrated only minimal use of community facilities among those studied, Donegan & Potts (1988) found that the people in their study didn't use local facilities, despite both

being knowledgeable about what facilities were available locally and possessing an ability to use them.

Still on the whole, it is accepted that largely positive outcomes exist in relation to the use of community facilities. Yet the nature of this use, where studied, has revealed somewhat less convincing findings, particularly in relation to participation in community activities. One study showed that the use of community facilities only happened at special segregated times, and consequently concluded that most people with intellectual disabilities still spent the majority of their time outside the home in segregated day activities (Raynes et al. 1987). As well as social segregation characterising people's involvement with community facilities and activities, their community presence was also largely dependent upon the availability of someone to accompany them. One study by Hill, Rotegard, and Bruinicks (1984) found that an average of only 39% of residents in community based accommodation could venture into their local neighbourhood on their own. The lack of somebody to accompany the residents was found to be the major impediment to their engaging in increased activities beyond the home, and as a significant consequence of this, the leisure activities people most frequently engaged in occurred within the home. These findings support a number of earlier studies which all found that the residence was the main venue for activities.[2] In a study by Evans (et al. 1987) which defined community as outside of the living setting and not in any other mental handicap service, the percentage of time that people spent in the community ranged from just 2.9% to a high of only 16%.

The impact of community presence on social isolation

Although Emerson and Hatton (1994) were quoted earlier as saying that presence and participation have often been seen as the foundations of social integration, Jahoda (*et al.* 1990) recognised that:

> ...a vital question...which has rarely been addressed directly is the relationship between the participation of people with a learning difficulty in community activities and their achieving acceptance by, or forming reciprocal friendships with, non-handicapped people. (p. 128)

Jahoda's comment suggests it would be a mistake to assume that community presence would be likely to bring improvements in the extent of an individual's social isolation. Yet two authors have begun to address this issue by seeking to collect and consider more than just quantitative data on community presence.

Booth's study (*et al.* 1990) supports the notion that simple quantification of community presence, based on the number and variety of facilities and activities one frequents, does not allow for a more fine-tuned evaluation of the quality of these experiences, particularly how they relate to opportunities for reducing intellectually disabled people's social isolation. By considering the quality of community presence, it appears one can begin to tease out the relationship between these experiences and social isolation. Booth's study found that the observable increase in the use of community facilities was, in qualitative terms, an increase in the use of *functional* services rather than *social* opportunities (p. 101). These findings suggest that the qualitative nature of community facilities used, and the activities participated in, is likely to be a central consideration in determining whether evidence of community presence can be taken as an indicator of community

integration being achieved, and the problems of social isolation as well as physical segregation being addressed.

In addition, Walker (1995) also suggests that the nature of community involvement affects community contacts. In particular, she argues that it is important to consider the extent to which the facilities or activities within the community that people engage in:

> a. Include people who are either heterogeneous or homogenous;
>
> b. Are characterised by social anonymity or social interaction; and
>
> c. Are characterised by people sharing common or diverse interests. (p. 178)

Walker's hypothesis suggests that the reason social isolation may change little, despite clear increases in intellectually disabled people's presence within their communities, hinges upon the nature of this involvement. Where Booth found that people's involvement was largely functional, rather than social, Walker confirmed this, but also went on to illustrate why involvement based on functional agendas typically yields few and poor opportunities for social interaction.

Like Walker, deKock (*et al.* 1988) found that while people living in small group homes had approximately 250 community contacts per year, a staggering 54% were based around shopping, an activity not likely to stimulate extended social interaction. Two other studies found that the nature of community facilities used allowed for little contact with ordinary members of the community (e.g.. walking in parks) (Lowe & de Paiva, 1991). According to Saxby (*et al.* 1986), although evidence of meaningful participation in shops, pubs, and cafes can be found, rates of interaction with ordinary citizens in these types of venues is low. Overall, the use of

community facilities has rarely been linked with significant social contact with local community members.

Conclusion

The findings presented above, which summarise intellectually disabled people's experiences of using community facilities and participating in community-based activities, taken together with the findings which demonstrate that the residence is often the main venue for activities, show that people with intellectual disabilities continue to spend relatively little time in the wider community and more importantly, even less time in community-based settings which either encourage social interaction or involve participation with wider community members. It is hardly surprising, given this, that what continues to be of major concern, in terms of the outcomes of community care for people with intellectual disabilities, is the length of time it takes people to develop social networks in the community (Korman & Glennerster, 1985). With this in mind, I turn now to the second broad consideration which community integration research has addressed: the problem of social isolation.

Findings on the task of ending social isolation

While the previous section illustrates that there is growing evidence that the *quality* of community presence significantly determines to what extent social isolation will persist or diminish, there is also evidence that this factor alone does not determine whether experiences of isolation will be replaced with those of full integration. This section of the chapter deals with the issues raised in existing research about the

social aspect of community integration. Although the intention was to make this section of the chapter a significant focus, the dearth of studies which address social integration has made this somewhat difficult. A good indicator of this is again, Emerson and Hatton's recent review of numerous studies related to relocation for people with intellectual disabilities, which found only 14% addressed social integration. However, there is evidence that very recently, this subject has been given increasing attention in the literature (Evans & Murcott, 1990).

The link between social integration and community integration

Thus far, in both the previous chapter and this one, I have touched on a number of interlocking themes which all appear to impact in some way on the community integration outcomes documented by existing research. However, no discussion would be complete without consideration of the problem of social isolation and its converse or remedy: social integration. In the previous section we have shown how physical integration can have only a superficial impact in the achievement of community integration. Atkinson and Ward (1987) summarised the view of many authors, saying:

> Sometimes we have been slow to realise that helping people settle into ordinary streets does not of itself bring integration into 'the community' or a high quality of life. (p. 242)

The slowness with which the field has come to recognise this probably explains why, for a long time, studies of community integration focused on community presence and physical integration outcomes rather than relationships and social integration outcomes. Yet recently, almost as often as relationships have been linked with community integration, they have been linked with quality of life and positive community adjustment.[3] As a result of this three-pronged argument in

favour of the importance of relationships, there has been a general consensus that intellectually disabled people's networks of relationships are a critical determinant of the substance of their lives. In addition, it is clear that not only researchers, but even more importantly, people with intellectual disabilities themselves consider relationships to be a prime factor in the level of satisfaction they feel with their lives. Le Touze and Pahl (1992) found that the most frequently mentioned source of satisfaction was other people, and consequently the main area of dissatisfaction concerned social relationships. Jahoda (*et al.* 1990) found that continued segregation and lack of opportunities to meet non-handicapped people were the main sources of dissatisfaction that intellectually disabled people expressed about their social lives.

The findings on social integration

In reviewing the range of studies addressing the social integration of people with intellectual disabilities, it seems that there are four stages in the process of social integration. The research findings are reviewed here in light of these four stages: contact; interaction; acceptance; and inclusion.

Stage One: contact

The problem of isolation, as the 1971 White Paper suggested (DHSS, 1971), is largely universal for people with intellectual disabilities. Researchers appear to concur on this. According to Evans and Murcott (1990), in addition to those who have lived in institutions, evidence suggests that "the vast majority of those with learning difficulties who may never have lived in institutions are also excluded" (p. 132). Lack of contact with the wider population has been a core aspect of this

problem. Jahoda (*et al.* 1990) found that people moving from both the family home and institutions had a low level of social contact with people outside their residences. Similarly, Hill (*et al.* 1984) found that few of the intellectually disabled people in their study had any regular interaction with non-handicapped members of the community, and only 15.8% had one or more monthly social contacts with a non-handicapped peer other than staff or family.

It seems that even for those receiving only visiting support, professional contact remained paramount. Flynn (1986) found that the majority of contacts made with ex-hospital residents' living independently were made by people in support services, while Evans (*et al.* 1987) found that contact with staff increased and contact with non-handicapped people remained low after relocation. In terms of family contact, Booth (*et al.* 1990) found that relocation to the community made little difference to patterns of family visitation, while Hill (*et al.* 1984) found that the average amount of family contact in a year was just one to three visits. Overall, it seems the contact between people with intellectual disabilities and members of the wider community which has been achieved by community care is generally superficial and infrequent. Consequently, despite relocation, the majority of intellectually disabled people's networks of relationships continue to be made up largely of staff (Evans & Murcott, 1990).

In one study, a man who lived on his own regretted the absence of social contact, saying:

> It's very difficult being a handicapped person. A handicapped person shouldn't live alone. How do you expect a handicapped person to live outside? (Atkinson & Ward, 1987, p. 235-6)

Yet isolation through lack of contact with others appears to be just the first layer of the problems facing people with intellectual disabilities. Where contact is possible, it seems the nature of the social contact people with intellectual disabilities typically have is often unfulfilling or even unpleasant.

Stage Two: interaction

While proximity is not necessarily likely to lead to more frequent interaction, it seems even where opportunities for interaction exist, this can sometimes exacerbate rather than reduce the sense of *felt* isolation that people experience. In particular, Richardson & Ritchie (1989) found that despite apparently active social lives, in that people were very seldom alone, many did not necessarily have the company they wanted. Atkinson and Ward (1987) found that the interviewees in their study were unhappy with the tensions of group-home life, and were intent on using their energies to build up outside contacts. For example, one man's group home was described as "not a happy and supportive environment" and this man was said to be "taking refuge" when he went to stay with his sister and aunt (p. 236). It seems that the very limited range of contacts and connections that typifies many intellectually disabled people's social lives, can often mean dissatisfaction characterises a significant number of the social interactions people have. Kaufman (1984) reminds us that evaluations of satisfaction should take account of the full range of people's feelings, from overt pleasure to acceptance, to resignation about one's situation. It seems that in many of the studies cited in this section, people with intellectual disabilities were resigned to their social lives and relationship networks. Despite overtly appearing to be unisolated, they may have *felt* isolated as a consequence of poor interaction opportunities.

In addition, there is some evidence that greater interaction with members of the wider community can lead to negative and hostile reactions (Abraham, 1989). In addition to problems with interaction within the home, people with intellectual disabilities have sometimes also experienced unsatisfactory results in their interactions with local community members. Flynn (1987) found that people living independently had problems socially with local people. This included various forms of victimisation like name calling and vandalism, mostly reported to be perpetrated by children or youths. In general, isolation from the wider community has been based on social exclusion. However, this exclusion appears more likely to result from clear lines of demarcation being drawn around people with intellectual disabilities *within* interaction, rather than from a complete absence of contact (Evans & Murcott, 1990).

Stage Three: acceptance

Although the previous section suggests that interaction does not always lead to acceptance, where it does, this outcome forms the basis for the achievement of full integration. According to Bogdan and Taylor (1987) acceptance is not based on the denial of an intellectually disabled person's difference, but on not impugning this person's character because of that difference. The extent of interaction one has with another appears to influence whether or not acceptance results: where interaction is limited or superficial, acceptance seems unlikely. For example, in a study of communities' acceptance of intellectually disabled people moving into their areas, where objection was voiced prior to people moving into the area (and thus, no opportunity for meeting or interaction existed), over 50% of the intellectually disabled people involved were described as not integrated a year later, and only 27% were judged to be treated positively by the community (Roycroft & Hames, 1990).

This study suggests that a lack of interaction, whether short-lived or on-going, leads to tolerance rather than acceptance, while Hogan (1986) argues that such opposition can be reduced by community residents who already live near to people with intellectual disabilities sharing their views with those expressing opposition. This argument suggests that interaction over time is likely to result in greater acceptance than may have initially been present among wider community members.

Where interaction is long-standing, it seems even the most significant differences can be overcome in favour of acceptance. Evans and Murcott (1990) claim that a degree of intimacy is required to become blind to difference. They quote Homans (1951) who argues:

> 'Friendliness' unquestionably conceals a complicated process. For one reason or another, you associate with someone for a period of time; you get used to him; your behaviour becomes adjusted to him; and his to yours; you feel at home with him and say he is a good fellow...You can get to like some pretty queer customers if you go around with them long enough. Their queerness becomes irrelevant. (p. 155)

Yet some authors point out that there is a distinction to be drawn between *polite* acceptance and *real* acceptance. Fred Davis (1961) describes "fictional acceptance" as often preceding genuine acceptance. He maintains that "in our society, the visibly handicapped are customarily accorded...the surface acceptance that democratic manners guarantee to nearly all" (p. 125). Davis goes on to say that this changes to genuine acceptance when the non-disabled person comes to view the disabled person as more like himself than not. Like Homans, Davis says the acceptance continues because the non-disabled person "suppresses his effective awareness of many of the areas in which the handicapped person's behaviour unavoidably deviates from the normal standard" (p. 130). Acceptance, although not automatic, appears to come from knowing a person well. However, very little

evidence can be found that suggests ordinary members of the public are adopting any kind of significant relationship with intellectually disabled people. (Evans & Murcott, 1990). Some, despite being well known in their communities, friendly, and possessing good conversation skills, find that the wider population will only "pass the time of day with them" (Day, 1988). For the most part, acceptance appears to remain at the *polite* stage.

Stage Four: inclusion

Moving from genuine acceptance to the final stage - inclusion - is represented in recent literature as the ultimate step in achieving full integration for people with intellectual disabilities. Atkinson and Ward (1987) found that where this did occur, it usually happened in one of two ways: via people with intellectual disabilities making a contribution to the community; or developing reciprocal relationships with others. While it is likely that reciprocity is one key to full social integration, reciprocal relationships are, as one might expect given the findings presented thus far, often not part of intellectually disabled people's lives.

Few people with intellectual disabilities appear to have relationships which involve either intimacy and reciprocity. This is evident in the numbers that are reported to have neither intimate nor special friends, the relationship types most typically associated with reciprocity. Hill (*et al.* 1984) found that an average of just 47% of the intellectually disabled people they studied had one or more intimate relationships or friendships, and that friendships outside volunteer programmes were rare. Booth (*et al.* 1990) found that for hospital and hostel movers alike, intimate friendships stayed low or non-existent after relocation. Atkinson (1987) found that while few people were willing to admit to having no friends, they were often forced

to extend their definition of friendship to include staff, acquaintances and volunteers. These findings are significant in attempting to understand why full integration is not a common experience for people with intellectual disabilities, and why the social support that comes with reciprocal relationships and acceptance (rather than tolerance) is not generally available.

While social support is important and largely invaluable to all of us, for people who need to rely disproportionately on support from others to manage their daily lives, the availability of social support often represents the only way that dependency on formal services can be minimised. Social support is defined by Whittaker (*et al.* 1983) as:

> ...enduring patterns of nurturance, in any and all forms, that provides contingent reinforcement for coping with life on a day-to-day basis. (p. 55)

According to Whittaker, people with intellectual disabilities "depend more on enriched sources of support than other people" (p. 383). Therefore, the extent to which their current experiences of community integration provide them with access to sources of social support represents a critical concern.

On the subject of social support, Abraham (1989) concluded that "spontaneous local contact will not provide adequate levels of support and involvement" (p. 121). While such a statement is in some ways obvious, it is the absence of other avenues to adequate support and involvement that makes this fact so critical for people with intellectual disabilities. As the result of limited and inadequate social networks, Atkinson (1987) suggests that people with intellectually disabilities may rely more heavily on this local contact than other people typically would, because they have few supportive relationships overall. Abraham (1989) says the tendency to rely on

locally based support might also result from having limited resources and poor mobility. Whatever the reason, it is clear that people with intellectual disabilities are often forced to rely, in an intimate way, on professionals or local relationships, which Argyle and Henderson (1985) say are relationships traditionally associated with the avoidance of intimacy.

Given this situation, Booth (*et al.* 1990) and Atkinson (1987) both conclude that the value of intimate friendship in the lives of people with intellectual disabilities cannot be overestimated. As well, Stainback (*et al.* 1987) makes the important point that greater numbers of friends are not necessarily more satisfying than a few, good quality relationships. As with community presence, simple quantification is not an adequate way to measure outcomes in the area of relationships.

Conclusion

Overall, the problem of isolation does not seem to be peculiar to any particular section of the intellectually disabled population. Neither place of residence, or previous place of residence, or intellectual ability seems to make a difference in outcomes related to social isolation. People living independently, in family homes, in group homes, or in hostels have all been shown to experience isolation. Lundstrom-Roche (1981) found that people living in the family home led restricted lives which revolved around their family and the services organised for them. Other studies of people living in the family home found their social lives to be limited, and very few were found to have non-handicapped friends.[4] As well, people who have moved from either the family home or from long-stay institutions have been shown to suffer similar experiences of isolation. Cattermole (*et al.* 1990) found that those

who moved from home and hospital alike were dissatisfied with their social lives both before and after relocation. In terms of intellectual ability, people with severe and profound intellectual disabilities have been shown to suffer isolation (Rawlings, 1985 & 1985a). Yet, even people with mild intellectual disabilities have experienced significant isolation. Edgerton's classic study, *The Cloak of Competence* (1967), found that very able people discharged from hospital experienced a great degree of isolation, while recent studies by other authors have drawn similar conclusions.[5]

The message to be drawn, from the literature then, is that the problem of social isolation is largely a universal experience for intellectually disabled people. There is little surprise then in the fact that community integration outcomes have been consistently poor. Reversing these outcomes will first require an understanding of the factors which have contributed to the nature of these outcomes. Day (1988) makes it clear that considerable adjustment will be required for people moving from an institutional setting to truly take their place in the community. Bogdan and Taylor (1987) on the other hand, contend that we should be concerned more with the converse of adjustment: acceptance. This statement illustrates an important distinction between the possible routes to redressing poor integration outcomes. If one accepts that both adjustment and acceptance are important considerations in promoting community integration, then it becomes clear that both people with intellectual disabilities and those around them (mainly members of the local communities where they move) will have to change in some way to make full integration possible.

In response to this dual challenge, some may take the view that full integration is unrealistic for people with intellectual disabilities, and advocate instead for

relationships and community to be encouraged *among* people with intellectual disabilities. Others who embrace the challenge argue that full integration does not have to be an either-or proposition. While Evans and Murcott (1990) concluded that people with intellectual disabilities tend to interact with either the world of disability or the world beyond, but rarely both, Atkinson (1987) found that people having friendships with other people with intellectual disabilities did not preclude them from having friendships with non-disabled people. Given this, it seems full integration is theoretically possible. And given that many in the field accept this, much attention has been paid more recently to contemplating *why* the largely disappointing findings reviewed thus far in this chapter have occurred. I now turn to this question in the second half of this chapter.

Part Two: Contributing factors in the documented community integration outcomes

Introduction

In considering the literature as a whole, it seems the two schools of thought suggested above by Day (1988) and Bogdan and Taylor (1987) are broadly used as a means to explain what contributes to the disappointing community integration outcomes described in the previous section of this chapter. One school of thought leans more toward identifying the problem as *a lack of adjustment* among people with intellectual disabilities; while the second maintains that these poor integration outcomes result largely from *a lack of acceptance* of people with intellectual disabilities as full members of our communities and of the larger society in which

we live. The popular arguments put forward as part of either the adjustment or acceptance perspectives are discussed below, as is the one unique explanation which appears to transcend these opposing perspectives.

The challenge of adjustment

Arguments which seem to lend credence to the adjustment perspective appear to reflect the medical model of disability, which associates the consequences of disability with the inherent 'condition' of the disabled individual. Chapter Two revealed that disabled activists regularly reject this notion; however, authors that support the adjustment perspective identify some intrinsic qualities, argued to be typical of people with intellectual disabilities, as key factors in their inability to achieve full integration.

Whittaker (*et al.* 1983), in his discussion of the social support networks of people with intellectual disabilities, embraces the adjustment perspective when he readily pre-empts his comments by acknowledging that they are made "at the risk of blaming the victim." He contends that it is the "defining characteristics" of intellectually disabled people that prevent them from building and making full use of social networks (p. 395-6). Whittaker goes on to support this by arguing that intellectually disabled people's intrinsic needs, dependence and personality traits render them less able to make and maintain relationships. He describe the typical characteristics of people with intellectual disabilities as incompatible with relationship development and maintenance, saying these people lack social competence and energy, demonstrate a general lethargy, and are unable to reciprocate in relationships with others (p. 396).

Stainback (*et al.* 1987) shares the view that people with intellectual disabilities often lack the social skills necessary for developing and maintaining relationships, although this author's position reflects greater positivism about the potential for these people to learn these skills. Stainback argues that people with intellectual disabilities should be taught to exhibit behaviours which have been found to contribute to the development and maintenance of friendships (p. 18). The feasibility of this approach is supported by Duck, a social psychologist, who argues that because developing and maintaining relationships are skills, both teaching and opportunities to practise what is taught can promote the development of these skills (Duck, 1983).

Finally, Whittaker (*et al.* 1983) also suggests that people with intellectual disabilities possess a certain predisposition which makes them both relate more easily to other disabled people, and prefer the opportunity to socialise with their developmental peers (p. 389). While some argue this is an innate predisposition, others see it as more circumstantial in origin. Although intellectually disabled people are likely to be attracted to each other for the same reasons any two people would be (because they share common interests, experiences and opportunities for contact), Stainback (*et al.* 1987) points out that an intellectually disabled person's apparent *preference* for relationships with others who have intellectual disabilities may be more accurately interpreted as an indicator of the extent to which opportunities to share common interests, experiences and opportunities with non-disabled peers are lacking. This emphasis on the importance of opportunities brings me to considering the second perspective - a lack of acceptance - as a possible explanation for the poor integration outcomes typically observed.

The challenge of acceptance

Contrasting the above arguments, which are predicated on the assumption that the intrinsic deficits of people with intellectual disabilities are largely responsible for their failure to achieve full integration, a number of authors have suggested that a better explanation might be one based on the social model of disability. In this model, one's inability to succeed in society is explained by evidencing the restricted opportunities that people have to participate. People's intrinsic abilities are considered to be less critical than opportunities in determining success.

Generally, this perspective emphasises the lack of opportunities that people with intellectual disabilities have to develop relationships with others and through this, to engender others acceptance of them. Restrictions on opportunities appear to result from three general areas: physical barriers; a lack of adequate support and resources; and others' refusal to allow a person to participate with them. Within these broad areas, research studies have found that problems with opportunities to participate in wider society have been associated specifically with: the segregating nature of day activities; lack of transport; poverty; poor leisure options; lack of family involvement; negative reactions from the wider community members; and community involvement, where it does occur, that emphasises functional rather than social participation.[6]

The absence of adequate, practical support to extend an intellectually disabled person's social circle beyond the world of disability often results in little increase in the acceptance of that person by the wider community. Some authors have argued people with intellectual disabilities need real opportunities for friendship development and this includes opportunities to be a friend to others. Stainback (*et*

al. 1987) notes that people with intellectual disabilities are "often provided little encouragement or opportunities to provide comfort, support and assistance to others" (p. 21). His contention is that we have focused too much on helping disabled people rather than encouraging them to help others as a basis for encouraging positive relationships.

Similarly, it seems we may have also spent too much time trying to assist people with intellectual disabilities to join in, and not enough time trying to encourage the wider community to do the inviting. Some researchers acknowledge that social networks remain largely inaccessible to people with learning disabilities because of...the suspicion or indifference that they encounter (Le Touze & Pahl, 1992). Although encouraging people with disabilities to be better friends to others may result in more relationships, it is also true that intellectually disabled people do better in the development of friendships when they are surrounded by "people who initiate warm and accepting social interactions toward them" (Rubin, 1980). Clearly, encouraging acceptance involves promoting opportunities for people on both sides of a potential relationship to engage each other in positive ways.

A shared point of agreement

In some sense, both the adjustment and acceptance perspectives have merit in explaining the possible reasons why poor integration outcomes have resulted for many people with intellectual disabilities. To ignore one or the other in attempting to redress these outcomes would seem unhelpful and likely to be damaging to whatever efforts are made. When the issues of adjustment and acceptance are considered collectively, one can identify a consistent emphasis upon *the need for*

more positive intervention, whether it be to address problems of adjustment or acceptance, to overcome social isolation and progress toward full community integration.[7] Coupled with this shared consensus about the need for more positive intervention, the literature has also increasingly presented considerable evidence that direct support staff are likely to play a pivotal role in the community integration outcomes which evolve for the intellectually disabled people they support. Wolfensberger and Thomas (1994) firmly suggest that failings in this area represent the primary problem, saying:

> If service providers are not willing to establish, as a priority, efforts to build viable, relatively unconditional supportive relationships for service-users, laws can be passed, unlimited funds can be allocated and still - nothing will work. (p. 56)

However, a number of factors have inhibited both researchers' and practitioners' awareness of the critical role that direct support staff have to play in community integration outcomes. Research on this subject was generally slow to develop for reasons explained earlier. In addition, because traditional assumptions (which suggested that physical presence constituted integration) took a long time to be dismantled, findings related to participation and relationships were slow to evolve. This meant there was less emphasis on the nature of support being provided by staff; consequently, the critical role they had to play in community integration went unrecognised. However, the first step in the process of awareness came when studies began to acknowledge the role of staff generally in determining the nature of the outcomes which accrued for those they supported.

While a number of very early studies which focused on long-stay hospitals, stressed the importance of staff interaction with residents in stimulating gains in the comprehension, expression, conversational, and social skills of those residents,[8] the

critical role of staff seemed to get lost in many people's aspirations for what a move from these settings could achieve. More recent studies by Rawlings (1985 & 1985a) have addressed this inappropriate emphasis on the importance of place. Rawlings found that the geographic location of a residence has little effect on people's quality of life compared with factors such as staff autonomy and initiative, improved staff ratios, and more service user-oriented practice by staff.

Coupled with this growing emphasis on the importance of staff generally, research also began to show evidence that community integration outcomes were not simply dependent upon issues of adjustment or acceptance. Hill (*et al.* 1984) found that the lack of staff to accompany the residents was reported as a major impediment to their engaging in increased activities, while Evans (*et al.* 1987) attributed gains in community involvement more to the commitment of staff than to the training of individual residents. These findings, combined with others which repeatedly demonstrated that integration was not an automatic consequence of relocation, opened the door for staff to be considered a critical factor in determining community integration outcomes.

The evidence in relation to staff

Findings from transition studies

Awareness of the critical role that staff have to play in explaining community integration outcomes for those they supported evolved, at least in part, from the early focus on transition. This specific focus brought a recognition that institutional living was strongly connected with intellectually disabled individuals becoming dependent on staff (Atkinson, 1980), and research found that this was likely to continue after relocation to the community (Booth *et al.* 1990). From this, researchers concluded that successful transition to community living could not happen without the continued involvement of staff and the support system they provide, both to avoid those moving becoming isolated and lonely (Atkinson, 1983), as well as to offer opportunities and guidance in developing relationships with members of the wider community (Atkinson, 1988).

Recognising the importance of staff's involvement

Beyond transition, it was recognised that the critical role for staff continued. Some authors emphasised the impact that direct support staff particularly have on service outcomes. According to Felce and Toogood (1988):

> the responsibility for service quality lies more with the staff than with the managers or providers of the service...not only is the quality of the service largely in the hands of these front-line staff, so too is the safeguarding of service quality. (p. 188)

Similar findings can be found in relation to community integration outcomes specifically. According to Atkinson (1988), staff must continue to be involved:

> ...in maintaining friendship links, fostering new relationships, and providing day-to-day support. The quality of people's lives and the richness of their community experiences, will not then be seen as an individual responsibility (or personal 'failure'), but as a shared challenge. (p. 10)

In support of this assertion, Humphreys (*et al.* 1987) found that for many individuals with intellectual disabilities, there was significant evidence that they were "solely dependent on staff for creating opportunities to develop social networks outside the world of handicap" (p. 128). This appeared likely to be connected to the fact that, as a number of studies concluded, people's main source of support typically came from official carers rather than more informal community contacts.[9]

Walker (1995) argues that "the way support is provided by...service system staff can have a significant impact on a person's social network... Support can either be restrictive or facilitative" (p. 189-90). The idea that staff can act in either "restrictive or facilitative" ways has been increasingly addressed in the more recent literature on community integration outcomes. Although a facilitative approach is clearly preferred, the approaches of staff often appear to fall considerably short of this.

Beginning to identify where staff support has failed

The support provided by staff has been criticised for a number of reasons. According to the British Columbia Association for Community Living (1988), the support is often inadequate: "people have been given few opportunities to meet

other and make friends (and) people are not assisted to maintain the friendships they have formed" (p. 4) In addition, the Association suggests staff may not provide support to develop relationships on the basis that they do not consider those they support capable of having intimate loving partnerships or even needing them. Lutfiyya (1988) argues that:

> adequate support in opportunities to meet and interact must be provided to both the person with disabilities and the typical people involved. Where this has not happened, it is largely due to staff's failure in their role. (p. 3)

Staff support has also been described as inappropriate. Again, according to the British Columbia Association for Community Living, "people who work in human services are more often programmers than facilitators (and) people are often supervised constantly" (p. 4) Richardson & Ritchie's study (1989) found that this was also the case here in Britain. By far however, the strongest condemnation of staff has been to describe their actions as inhibitive. According to Lutfiyya (1988):

> ...most human service programs effectively set up barriers between people with disabilities and most people in their community. Even when people with disabilities may be physically present in a community, a variety of circumstances conspire to keep them apart from their neighbours, (like for example) program rules and restrictions... (p. 5)

The findings of Hill (*et al.* 1984) support Lutfiyya's claim: they found that in some cases, policies of the community residence were reported to have discouraged family contact. In addition, they made the important point that leisure, family, and social activities may often "be curtailed by regulations that tend to focus on physical and habilitative aspects of residential programs" (p. 279). A further indictment of staff actions can be found in Le Touze & Pahl's study (1992), which found that staff sometimes stopped people from going to what they consider 'unsuitable' events. As a result, people were described as facing "isolation in a sort of social limbo" (p.

146). LeTouze and Pahl concluded that "people do not just need advice and support but the chance to experiment and discover for themselves by trial and error" (p. 146).

Some authors maintain that staff are obstacles to community integration because they refuse to give up control. According to Lutfiyya (1988), as staff introduce people with disabilities to more people, they must also give up some of their control over these people's lives. She goes on to say that "the excessive control that human service staff now exercise over the people they serve would be socially inappropriate in the types of relationships that we wish to encourage. We must constantly pay attention to the differences between adequate support, guidance and protection, versus over-protection that unnecessarily restricts a person in his or her movements and associations" (p. 4)

A number of authors suggest that the personal attitudes and beliefs of staff affect what they do. Wolfensberger and Thomas (1994) argue that both personal and professional attitudes and beliefs clearly make some qualified practitioners less likely to help those they support to achieve social integration. They describe these things as part of the "peculiar identity and functioning of contemporary human service workers who are of professional identity" (p. 53). Although this may exclude many direct support staff, the issues raised are largely about professional boundaries and role maintenance, and are therefore likely to be relevant to this group of staff as well. Wolfensberger and Thomas maintain that "many professional human service workers are deeply distrustful of ordinary citizens, sceptical and pessimistic as to what such citizens can and will do, and very unrealistically prideful of their own capacities" (p. 53). Although Peter Newnes (1994) claims this may be due in large part to maintenance of professional role boundaries rather than

arrogance or confidence, he agrees that the scepticism and pessimism evident in professional attitudes toward ordinary citizens may be common. Hutchison and McGill (1990) supports this claim, saying that one of the biggest myths in this field is the fact that ordinary community members have no interest in relationships with devalued people (p. 21).

Newnes (1994) also suggests these negative stances toward the wider community are "actually a defence against profound insecurity in the awesome role of being a helping professional" or that "calling on ordinary citizens would be detrimental to their professional role" (p. 59). Whatever the reason, as a result, they do not call on ordinary citizens to get involved in the lives of devalued people, even where they might be better than workers at something; and they are less apt to seek and support normative integrative experiences for their clients (Wolfensberger & Thomas, 1994). Overall, a number of authors clearly agree that for whatever reason, professionals are reluctant, and in some ways unable, to assist those they support to integrate into their local communities. Consequently, they often do not engage in this type of work with their clients.

The tensions around facilitating or providing friendship

Still another reason why staff may not engage in the work required to help people build wider relationship networks is suggested by Evans and Murcott (1990). They found that staff were strategically involved in one of two ways: "either staff attempted to establish relationships on behalf of those with whom they work or they themselves adopted the position of surrogate friends - although in practice it seemed more like a parental role" (p. 127). They also found that staff "occupied the key social roles with whom those with learning difficulties relate and thus constitute the

main members of their social network" (p. 127). Judith Snow, a disability writer and theorist, suggests a logical explanation which one could apply to these findings, saying that if staff feel they are meeting the needs for friendship of those they support, little effort to facilitate other friendships will be made (1990, p. 28).

The debate over what is an appropriate role for staff has however, sparked varied reactions in the field. Rather than objecting to staff providing friendship to those they support, the British Columbia Association for Community Living (1988) is critical of the fact that staff who work in human services rarely have a genuine personal relationship with those they serve. Hill (*et al.* 1984) expressed dissatisfaction with the fact that only 10% of the people in their study had friends who were staff members and with whom they spent time during the staff's off-duty hours, while in addition, only 1% had friends among staff who no longer worked at their residential facility. Yet Judith Snow (1990) disagrees that these types of friendships should be encouraged, saying that while human services should help relationships to happen, they should not actually provide them because this would confuse the roles of a friend and a staff or support person. One reason why a scenario, in which staff act as friends to those they support, is seen as unacceptable is that many people with intellectual disabilities will not then be able to enjoy the same continuity in their relationships. Wolfensberger & Thomas (1994) describe the likely result as a 'relationship circus' in which paid staff can typically be found "dancing in and out of people's lives" (p. 55).

Can staff make a positive difference?

One may well find him/herself facing exasperation at this point, having accepted the need for positive intervention yet struggling to find any evidence that suggests staff can be a positive force. John McKnight (1987) has reacted with seeming hopelessness to this prospect by taking the stance that "human services cannot and should not play an important role in promoting friendships: human services should allow relationships to happen, but not actually take on the role of facilitating them, for fear of perpetuating control in an area that should not be controlled" (p. 25). This is, in many ways, a rather narrow and hopeless attitude, and it seems that few other writers take such a dismal view.

In particular, for people with few if any meaningful relationships in their lives, staff intervention is accepted as essential (Forest, 1987). Also, Atkinson and Ward (1987) maintain that staff may be able to help a preliminary acquaintance develop into a deeper relationship or friendship by offering hints on how to move forward socially. Firth & Rapley (1990) argue that "service workers have much to contribute in helping create opportunities for people to develop friendships and relationships" (p. 158). Despite these positive hopes, outcomes have clearly fallen short in this regard. McConkey (*et al.* 1982) calls for more research and investigation to be undertaken, saying:

> We need to look seriously at the preparation and opportunities we give handicapped people for becoming involved in social activities outside their work and away from their homes. (p. 93)

Within this, however, it is important to recognise that two factors are likely to impact upon the role of direct support staff in this regard: agency support and the responses of ordinary community members.

The need to give attention to factors likely to influence staff

There is a body of literature that suggests agency management has a direct influence on the attitudes, morale and work practices of direct support staff. Management is said to have an influential role in both guiding the development of staff attitudes and maintaining continuity between those attitudes and staff practices (Booth *et al.* 1990a). According to Shalock and Kiernan (1990):

> The maintenance of a relationship between the values base that an agency purports to operate its service upon, and the presence of an ordained structure to support staff in putting those values into practice, is the key to a quality service; and one that is the primary responsibility of any agency management group. (p. 187)

Indeed, it seems the on-going presence and leadership offered by senior members of staff determines how much staff feel compelled to put their values into practice (Sinclair, 1975). Booth (*et al.* 1990a) suggests that strongly held attitudes, demonstrated by senior staff, would likely challenge direct care staff to clarify and act upon their values for practice in a more consistent and conscientious way. Further, according to Cawson and Perry (1977), senior staff who do not face the pressure of daily contact with clients, are able to adopt and assert more liberal attitudes. These senior staff attitudes can have an impact upon the quality of a service, independent of the nature of the institutions or agencies within which these attitudes are expressed (Rawlings, 1985). As part of changing or static services, there appears to be clear evidence that senior staff can influence the attitudes, morale, and practices of the staff they supervise.

In addition to senior staff, the agency's organisational structure, and the extent of decentralisation present, can also affect direct support staff's attitudes, morale and practices. Numerous pieces of research in this regard have linked decentralisation

of authority to more resident-oriented and positive care practices[10], which may well be related to the fact that decentralisation has long been associated with higher levels of staff morale and more positive attitudes (Oswin, 1978).

In terms of the attitudes and actions of ordinary community members impacting upon direct support staff, the literature on this appears extremely limited. According to Seltzer (1985), the subject of community opposition has not received adequate attention by researchers. The literature that does exist is generally focused upon identifying causes of opposition and offering proscriptive hindsight about how to minimise this in the future. Although important, little work has been done in addition to identify the *consequences* of community opposition for staff who support people with intellectual disabilities, although it seems likely that their work on developing relationship networks in particular would be affected by the actions and attitudes of the community. Not only is it likely that the attitudes and morale of staff will be affected, but it is equally likely that as a result, the tangible community integration outcomes for the people with intellectual disabilities being supported by those staff will also be affected.

Chapter Conclusion

It seems clear that the role of staff, taking into account the effects of the agency that employs them and the local community where they work, needs to be further explored if the less than positive community integration outcomes are to be improved in the future. Findings thus far demonstrate that intellectually disabled people's experiences of both physical and social integration are distinctly limited

and often not satisfying. In some cases, the residence continues to be the main venue for activities, and often, segregated day and leisure opportunities remain the norm. Consequently, people spend relatively little time in the wider community, and even less time in settings which encourage social interaction or participation with wider community members, which ultimately means that social isolation from life beyond the world of disability continues to plague many intellectually disabled people.

The need for positive intervention in the face of these disappointing outcomes is hardly disputable. What kind of intervention remains the subject of debate, with arguments in favour of encouraging greater adjustment contrasting those which emphasise facilitating greater acceptance. It is likely many would agree that both perspectives are important. Peter Willmott (1987) provides a useful understanding of how new relationships develop which supports the notion that both adjustment and acceptance are important considerations. He names four factors as being essential for any new relationship to develop: on the side of adjustment, he names skills and motivation; and on the side of acceptance, he names opportunities and mutual attraction. Clearly, positive intervention must take a number of forms if it is to be effective. Although the question of what type of intervention should be emphasised may be debated, there seems to be significant consensus on the question of *who is best placed* to make this positive intervention.

There is a wealth of evidence in the literature which demonstrates the critical role that staff have to play in the lives of those that they support. In part this is due to the fact that the support available to people with intellectual disabilities continues to come from official carers rather than more informal networks. To change this, and consequently relieve the likelihood of over-dependence, it is clear that staff

themselves must help people extend their social networks and thus, broaden the sources of support available to them. In this way, unhealthy dependence can be replaced with healthy interdependence which can empower intellectually disabled people by providing them with a range of sources of support to which they can turn.

Finally, the nature of intellectually disabled people's relationship networks has been shown to be a critical factor in determining their quality of life, community adjustment and community integration. As well, this is one of the few areas, of those that social researchers investigate, that people with intellectual disabilities themselves feel is of significant importance to their lives. We seem to know a great deal about what is ***not*** being done and achieved in terms of relationship networks; and equally, we know how much success appears to be dependent on the role of direct support staff. Yet we know far less, as the result of empirical research, about ***why*** many staff are not embracing the need for positive intervention and are therefore failing to facilitate positive outcomes. If this question cannot be answered, it seems there may be little hope of rectifying what may be the most critical factor in determining the quality of intellectually disabled people's lives and their experiences of living as fellow citizens in our communities. This study is designed to address this vital question.

[1] See Bell & Schoenrock (1981); Willer & Intagliata (1982); Conroy (*et al.* 1982); Locker (*et al.* 1983); Felce (*et al.* 1986).

[2] See Gollay (*et al.* 1978); McDevitt (*et al.* 1978); Malin (1982); Crapps, Langone & Swaim (1985).

[3] See for example Atkinson & Ward (1987); Evans & Murcott (1990); Evans (*et al.* 1987); Hill (*et al.* 1984).

[4] See for example Cattermole (*et al.* 1988).

[5] See for example Flynn (1987); Atkinson & Ward (1987); Jahoda (*et al.* 1990); Atkinson (1985).

[6] These findings are discussed in studies by: Le Touze & Pahl (1992); Firth & Rapley (1990); Atkinson & Ward (1987); Atkinson (1988); Walker (1995).

[7] A number of authors have written on this subject and concur on the need for more positive intervention. Some of the most well known include: DorothyAtkinson, Roy McConkey, Michael Bayley, John & Connie Lyle O'Brien, Marsha Forest, David Schwartz, and Angela Novak Amado. Their relevant published work is cited in the bibliography of this thesis.

[8] See for example King (*et al.* 1971) and Raynes, Pratt & Roses (1979).

[9] See Gollay (*et al.* 1978); McDevitt (*et al.* 1978); Malin (1982); Crapps, Langone and Swaim (1985).

[10] See King (*et al.* 1971); Holland (1973); Blau (1970); Raynes, Pratt and Roses (1979); Goffman (1961).

PART TWO.

The Study Explained

CHAPTER FOUR

"The Study Design"

Introduction

The preceding three chapters have outlined the struggle to develop community care, the struggle to acknowledge and agree upon the importance of community integration as a principle for community care, and the way in which intellectually disabled people's experiences of community integration have been, in the face of these struggles, predictably unsatisfactory. This process of scene setting has moved from general to specific and from policy to practice, charting a number of the critical issues that have some part in explaining the community integration outcomes which appear to be typical for intellectually disabled people today.

This journey has culminated in a recognition of the need for *positive intervention* to redress the existing pattern of integration experiences for people with intellectual disabilities. This recognition has contributed to the growing awareness of the vital role that direct support staff have to play. Chapter Three demonstrates that considerable evidence already exists which suggests that staff are likely to have a critical role to play in determining community integration outcomes for the intellectually disabled people they support.

Yet designing a study to advance our knowledge of such issues requires more than a basic understanding of the problems which exist and a commitment to searching for solutions. In particular, any study must begin by adopting a perspective on the purpose and parameters of conducting social research. Therefore, I deal with this issue in the first part of this chapter by considering how my own understanding of social science and my background in social work have influenced this study's development. I then discuss, by way of summary, the key conclusions I've drawn from the existing body of literature which addresses community integration outcomes for people with intellectual disabilities. In part two of this chapter, I go on to introduce the study's objectives and research questions, in light of both the ideas presented in part one and the evolved definition of community integration promised in Chapter Two. I conclude the chapter by explaining how the choice of design was ultimately made.

Part One: Adopting a perspective for the study

Reflecting on the positivist and interpretive debate

Early thoughts around developing this study involved considering the fundamental debate between positivistic and interpretive research paradigms. I was aware that within the social sciences, these approaches have been cast in opposition to each other, and much energy has been expended to argue for the superiority of one or the other approach. The debate seems to stem largely from the positivistic notion that social science research can generate causal laws like the natural sciences. The interpretive paradigm argues that by making this claim, positivism fails to

acknowledge the essential subjectivity of humans, and consequently produces explanations which may be presented as proven truths but which are more likely to be false. The interpretive paradigm is founded upon the notion that not only are human research subjects essentially subjective, but that this subjectivity also applies to the researcher. In this argument, the researcher cannot be an objective observer because he or she cannot avoid bringing assumptions and biases to the research endeavour. In addition, the interpretive philosophy extols the merits of an approach based on interpretation, asserting that valid research "involves more than mere observation...it requires an interpretation on the part of the observer" (Fay, 1975).

Within the social sciences, psychology remains heavily dominated by the positivist approach. Sociology, despite being founded on positivist assumptions, has moved strongly toward the interpretive paradigm. Although Cheetham (*et al.* 1992) acknowledges that there is no one research method which can best demonstrate social work effectiveness, researchers in social work have always struggled with the scientific imperative (Brekke, 1986). Nearly thirty years ago, Reid and Hanrahan's (1981) critical observation that social work's study of challenging social problems appeared to have been subverted by a quest for methodological rigour (Sheldon, 1986), sparked strong rejections of the positivist approach.

> In a misguided attempt to be scientific, social work has adopted an outmoded, overly restrictive paradigm of research. Methodological, rather than substantive requirements determine the subject matter to be studied. As a result, important questions and valuable data go unresearched. (Heineman, 1981, p. 371)

More recently, proponents of pluralistic evaluation like Smith and Cantley (1985) "argue that it is false to force the social work world into the traditional scientific model of evaluation which thrives on assumptions of objectivity, rationality and experimentation."[1] More pragmatic discussions around the use of experimental

designs in social work are typically cautious, emphasising the major practical and ethical problems which inevitably arise from these designs.

> In practice, the conceptual purity of the experimental design can often not be attained...thus, while the experimental design would not automatically be ruled out, the limits both of the conceptual philosophy in which it is rooted and of the practical requirements for its implementation would severely restrict the situations in which it might feature as a potential strategy. (Cheetham, *et al.* 1992, p. 25,36)

While the experimental design has its merits, not least of which is that it has been said to provide the field with its most secure results (Macdonald, *et al.* 1992), this design "cannot be made error-free...the most that we can hope for is the kind of critical interaction among people with different biases that will make each of us better aware of our own biases." [2]

In social work particularly, it seems that studies to determine the effectiveness of helping interventions cannot be done in a vacuum which takes no account of other factors which may affect the outcomes observed. The values of social work emphasise the need to consider any individual in the context of his or her environment, and a general consensus exists which maintains this approach should not be undermined by pressures from the wider field of social science to pursue positivist research. Robson's (1993) notion of 'real world research' is based on studying something in the actual context where it occurs, with an emphasis on solving problems and identifying where change is feasible (p. 2,11). Developing a study which competently addresses identified problems, regardless of whether they can be accommodated in a positivist model of inquiry, is an essential approach that many social work researchers must adopt as a consequence of the subjects they study. The 'social' in social work implies what Cheetham (*et al.* 1992) refers to as "the complexities of context" and precludes the objective testing which a laboratory

experiment might be able to achieve. Adopting an interpretive perspective allows greater opportunity for the complicated yet critical questions that often face social work researchers to be explored in a variety of ways that offer real insight to the profession. Objectivity in practice has always been something many social work practitioners readily accept cannot be achieved. It is little wonder that some social work researchers reject the positivist paradigm on much the same grounds.

Adopting a grounded theory-building approach

Simply adopting an interpretive perspective however, does not determine whether a particular study will be based on a deductive, theory-testing or a more inductive theory-building model of inquiry. An inductive model of theory-building is particularly useful when well-developed theories do not exist due to the newness of a subject. In this study, I took the view that the existing literature, which strongly suggests staff have a role to play in community integration outcomes, called for a study that would investigate staff's role in ways which could refine and elaborate existing understanding. In particular, I concluded that what was required was a study which would offer a tentative theory, grounded in evidence specifically collected to address the subject, and able to be tested for its generalisability through further research. I recognised that a grounded theory approach would fit well with the intentions of this study because it offers a unique framework for "understanding the actions of individual or collective actors being studied" (Strauss & Corbin, 1994, p. 274).

The credibility for me surrounding the grounded theory approach arises from three aspects. First, from its interpretive perspective that is empowering to those being studied:

> Involved is...an insistence that ours is interpretive work and, ...that interpretations must include the perspectives and voices of the people whom we study. (Strauss & Corbin, 1994, p. 274)

Second, a grounded approach asserts a plausible position about truth, saying that theories about the realities we observe:

> ...are interpretations made from given perspectives as adopted or researched by researchers...a given theory is therefore fallible..temporally limited, provisional, (and) never established forever; their very nature allows for endless elaboration and partial negation (qualification). (Strauss & Corbin, 1994, p. 279)

Third, the approach's internal logic is strengthened through a methodology underpinned by "the grounding of theory upon data through data-theory interplay, the making of constant comparisons, the asking of theoretically oriented questions, theoretical coding, and the (ultimate) development of theory" (Strauss & Corbin, 1994, p. 283).

A grounded approach is one that social work and other practice-based professions often follow as a model for studying the problems that face them (Strauss & Corbin, 1994). In terms of community integration for people with intellectual disabilities, this is a subject for which there is growing concern within social work about how more positive outcomes can be facilitated. Yet currently there seems a distinct lack of well-developed theories about the nature of staff's impact in this regard, despite a growing awareness of the fact that staff do appear to play some part in these

outcomes. Consequently, a study designed to generate a provisional theory about staff impact, using a grounded approach, seemed quite valuable to undertake.

Integrating the principles of social work research

The values of the social work profession offer their own additional guidance to researchers in the field. In this study of community integration, my social work background has had a significant influence on the way this study has been framed. In particular, two *guiding principles* associated with social work research have informed the nature of the research questions developed, and confirmed the validity of examining what existing literature suggests is the critical role that staff are likely to have in determining the community integration outcomes of those they support. These guiding principles focus on the need to study the effectiveness of professional interventions and to avoid individualistic problem definitions.

The need to focus on the effectiveness of professional interventions

The primary purpose of social work research is generally agreed to be concerned with improving outcomes for clients by studying the circumstances they encounter which cause them difficulty, and the effectiveness of the interventions which social work professionals make to help clients cope more ably with these circumstances. Those dedicated to research in the field of social work are acutely aware of the link between measuring the effectiveness of practice interventions and legitimising social work as a distinct helping profession (Cheetham, *et al.* 1992). Despite an acceptance of this connection between scientific investigation and professional legitimacy among social work researchers, there have been significant misgivings in

the field regarding the use of objective "science" to study that which is considered by many to be a largely subjective endeavor (Grinnell, 1988).

Yet while most agree that subjectivity cannot be removed altogether from social work practice, nor can objectivity be absolutely achieved in social work research, it is also the case that we cannot ignore the observations of our critics which suggest that social work has no objective base from which its practice evolves (Howorth, 1984). Embracing these criticisms is particularly important when conducting research in the field of intellectual disability, where traditionally, theoretical approaches to serving people with disabilities have come from medicine, nursing, and psychology: fields that readily demonstrate extensive knowledge bases derived from scientific research.

Although a professional *value base* is indeed an essential starting point for social work practice, criticisms of the profession have sparked strong calls for developing and relying upon a scientifically valid *knowledge base* for social work based on studies of effectiveness. In Britain, CCETSW states that:

> Qualifying social workers need a rigorous approach to the acquisition of knowledge...They must be able to conceptualize, to reflect, to analyse competing theories, ideologies and models of practice which will inform their work. (CCESTW, 1989)

It has become increasingly clear that subscribing to the values of the profession can mistakenly be interpreted as 'proof' of effectiveness, allowing social workers to simply rely on "good intentions" in serving people. This not only jeopardises the people being served, but also encourages scepticism about claims that social work is a unique and valid profession with a firm grounding for practice. Indeed, practising in the field of social work *without a knowledge base* is increasingly considered to be unethical since interventions could carry the potential to make clients worse off.

Grinnell (1988) points out that the major problem of operating without scientifically valid research on our impact, is that intuition and our subjective ways of knowing are largely unreliable, leaving us often mistakenly evaluating our practice in an optimistic light, which may not be objectively justified by the evidence. Prominent reviews by Fischer (1973) and Mullen & Dumpson (1972) that consider numerous studies on social work effectiveness appeared to confirm this hypothesis.

Despite these realisations about the importance of measuring the effectiveness of social work interventions, the profession is still thought to remain uncertain about what kinds of interventions work effectively. According to Cheetham (*et al.*, 1992):

> **Bold claims and harsh accusations are thus not substantiated and policy may be more influenced by reaction and fashion than by knowledge of its impact. (p. 1)**

Given these concerns, a professional knowledge base derived from research is deemed valuable because it enables practitioners to discriminate between interventions which are effective and those which are not. Reid & Hanrahan (1981) assert that "it is doubtless true that the real question to be addressed is, *how effective is a particular program with a particular type of client*" (p. 331). Measuring effective practice however, is not soley a question of showing that the tangible change intended has resulted. In the end, measuring effectiveness must involve an assessment of the intent and method, as well as the outcome. According to Brewer and Lait (1980), there continues to be "a vagueness which characterises the goals of much social work activity" with "the goals of intervention being either undefined or defined in such a diffuse way as to be meaningless" (p. 142). Effectiveness is ultimately a complex indicator which must address three distinct issues: the legitimacy of intentions; the ethics of interventions; and the extent to which intended outcomes have resulted.

Beyond simply determining whether an intended outcome is realised, determining effectiveness in social work, like the profession itself, seems inextricably linked to value judgements. This is not to suggest that objective studies of effectiveness are not vital to social work. Rather, these studies must take account of the way that values determine both interventions and intended outcomes, thereby influencing the ultimate conclusions drawn with regard to effectiveness. Yet what is even more important to consider in conducting social work reseach is that the professional value base does not *just* influence professional intentions, interventions and outcomes. Equally, and perhaps more critically for researchers, the values of the profession influence problem definition. This brings me to the second guiding principle of social work research which has proven important in developing this study.

The need to avoid individualistic problem definitions

In addition to the the moral dilemmas raised above, which seem to *support* the validity of undertaking social work research, yet another moral dilemma requires consideration. Recent writers alert social work researchers to the danger that we may often follow the familiar *blaming the victim* orthodoxy which typifies many fields of social research.[3] Kagle & Cowger (1984) argue that there is a tendency in social work research to define problems in an individualistic way, despite the profession's commitment to seeing the person in an environmental context. They maintain this slant in problem definition is usually done out of a desire to conduct a scientifically valid study, which will demonstrate the impact of professional intervention in the simplest and most efficient way (p. 349). Conducting a study which takes account of the variety of environmental factors that may influence a particular client's behaviour or actions, rather than pursuing a behavioural study that

emphasises individual pathology, makes it much more difficult to determine the impact of the social worker's intervention on an observed change in the client's circumstances. So although *blaming the victim* in problem definition might make it easier to demonstrate that social work intervention has been effective, such an approach in social work research "could significantly influence the knowledge base of the profession," ultimately resulting in the profession redefining "its mission, its social role, and its relationships with clients" in a way that "reinforces stereotypes and perpetuates the situation of powerless client groups" (p. 350). Interestingly, Macdonald (*et al.* 1992) found that there was little evidence to support the assumption that research based on individual pathology, namely behavioural and cognitive-behavioural studies, would necessarily involve an easier route to establishing validity than other types of studies.

In respect of people with disabilities, these victim-blaming tendencies seem even more likely to arise in research if active steps are not taken to avoid this in the early stages of designing studies. The vicitim-blaming ideology is strongly akin to the medical model of disability, which has long been the basis upon which research in the field of disability has been granted validity.[4] Consequently, it has proven extremely difficult to view disability as environmentally-manifested; and therefore, the widely held presumption that disability (and all that is observed in the behaviours and actions of disabled people) is an organic condition often prevails in research. A researcher's propensity to 'blame the victim' in the field of intellectual disability is therefore doubly likely to become reality. However, contemporary researchers, led by those who are disabled themselves, are beginning to challenge this.

Sally French (1994) is highly critical of individualistic, medicalised research which has been the tradition in the field of disability, and which has based its questions on impairment with no regard for social context (p. 136-7). She maintains that the way that disability is defined is a political decision, as is the setting of research questions (p. 138). She warns that inappropriate questions, which traditionally blame the victim by defining disability as an intrinsic impairment, will lead to unsuitable services being developed (p. 141). Rioux (1994) makes the important distinction that our tendency as researchers to focus on individual pathology has gone through two stages: that which deals with prevention and the more recent focus on treatment of the pathology. Neither is acceptable according to Rioux, as both blame the victim by locating disability within the individual (p. 3). She calls for a new, critical theory of disability which challenges the notion that our professional efforts to prevent or habilitate will actually result in ameliorating the condition and effects of disability (p. 5). This new theory conceptualises disability as social status rather than medical condition, and therefore challenges researchers to focus not on what's wrong with a disabled person, but on what is wrong with the society in which they live, and with the opportunities and supports they receive (p. 6).

However, Rioux is acutely aware of the fact that the victim-blaming tendencies in disability research are still predominant, commenting that "the early assumptions that individual pathology was the basis for research questions have not changed a great deal over the past century" (p. 3). Consequently, the challenge to develop research which respects social work's value base but also gains recognition from the collective disciplines which traditionally contribute to disability research, remains.

Drawing key conclusions from existing research

The final, and arguably most influential factor which has affected the development of this study has been the critical problems identified by the existing literature base. In reviewing the evaulative literature which exists on community care for adults with intellectual disabilites, my attention was drawn to the growing significance attributed to community integration as a theme for evaluating the success of community care initiatives. I was equally intrigued by the various ways that community integration has been defined by researchers, and how this has ultimately affected the nature of research outcomes. Even more important however, I was disturbed and moved by the documented experiences of community living for many adults with intellectual disabilities. Chapter Three demonstrates how the literature is overwhelmed with a sense of desperation. Stories of isolation and dissatisfaction with community living seem to abound. Some research paints a hopeful picture on the surface, but closer inspection reveals less convincing findings than one might have expected. Researchers' tendencies to focus on whether people are better off in the community than they were in institutions have detracted from more fundamental considerations of how the lives of people with intellectual disabilities compare to those of 'ordinary' citizens (Emerson & Hatton, 1994).

For the most part, my own practice experience in community care services for adults with intellectual disabilities rang true with the accounts from the literature. The broad problems seemed clear: the solutions on the other hand, were only just beginning to surface. Consequently, my intention in designing this research project, was not simply to provide additional evidence of these familiar experiences. My intention was to offer insight into *why* these experiences have evolved, what makes them likely to continue, and how those factors which evidence suggests contribute

to negative outcomes, need to change in order that more positive outcomes might develop.

In studying the literature, I not only accepted the disappointing findings on community integration which predominated, but also recognised the critical assertions (despite these findings) that:

a) the formation of friendships is essential if one's experience of community integration will necessarily involve positive outcomes;[5] and

b) the quality of intellectually disabled people's lives is dependent, in large part, on the quality of their relationships with others.[6]

My critical review of the literature then moved to determining what explanations for the negative outcomes had already been put forward. Through this, I discovered a significant emphasis on the role of staff in determining community integration outcomes. I found evidence of their significant role in determining the quality of intellectually disabled people's lives generally. Overall, the literature suggested that *staff are in a position to make community integration possible*; yet the outcomes in terms of integration still remain, for the most part, disappointing. My view then, on designing a study which would contribute something new to the existing body of knowledge on this subject, was similar to that of McConkey (*et al.*, 1982), mentioned earlier. I have paraphrased his observation to fit the intentions of this study:

> Researchers need to look seriously at the nature of the preparation, support and opportunities that direct support staff provide to individuals to become involved socially in their communities and develop relationships.

Summary

Four important considerations converged to influence the particular approach taken in designing this study. By far the greatest consideration was the findings from existing literature. With the critical role that staff have to play in the lives of the intellectually disabled people they support clearly established, it seemed that an intense look at both what staff do and why they do it would offer a contribution to existing knowledge that may well move services forward in facilitating more positive community integration outcomes for users.

Second, the need to focus on the effectiveness of professional intervention reinforced the initial decision to design a study which concentrates on the role, activities, and impact of support staff. Although residential support staff are not typically professionally qualified, Rubin and Babbie (1989) stress that the consideration of suitable questions or dilemmas to study should not be limited to the experiences of professionally qualified workers - but should consider the experiences of anyone in a helping role in social work.

Thirdly, the need to frame research questions in ways which do not implicitly *blame the victim* made a study of community integration experiences, as opposed to social adjustment, a value-sensitive way to address the dilemmas raised in existing literature. The broad topic of community integration which forms the basis for this study is therefore supported by research questions which emphasise environmental, rather than personal, factors that may affect the quality of intellectually disabled people's experiences.

And finally, a recognition of the value of developing a study within an interpretive and inductive theory-building framework contributed significantly to the study's design and data collection methods. In summary, this study has been designed with the intention to explore and evaluate the choices that support staff make about using particular approaches to support in certain circumstances, and the consequences of those choices: a perspective associated with grounded theory. Through this attention to choices and consequences, the vital business of taking account of intentions, while also demonstrating how outcomes for intellectually disabled people are linked to the nature of the support they receive, can be tackled.[7] From this, the profession's understanding of the subject can be refined and a provisional theory about the *nature* of staff's role in community integration outcomes can be developed.

Yet perhaps the paramount guiding principle for all social work research is the need to make contributions to the profession's knowledge base which are *relevant to its practitioners.* There has been increasing criticism of the practical approaches taken by social work researchers which suggests that responsibility for this significant gap between practice and research lies more with researchers than practitioners (Kane, 1982). Conducting research, with an intention to make research findings accessible and relevant to practitioners, is a principle aim of the grounded theory approach, and necessarily involves addressing *unanswered questions and unresolved dilemmas* which are of concern to those who work directly with clients (Grinnell, 1988). How this was achieved in this study's design is the subject of part two of this chapter.

Part Two: Overview of the Research Study

Identifying objectives for the study

The dilemmas which surround community integration experiences for adults with intellectual disabilities, and the need to understand more clearly the role which direct support staff have to play in resolving these dilemmas, have provided the basis for the development of this study. In attempting to contribute new knowledge to that which exists in the current literature base, this study has been designed to:

> -investigate the actions of staff and how they relate to the facilitation of community integration for those they support;
>
> -explore the nature of the attitudes of staff, and how they influence the actions of staff in relation to the facilitation of community integration for those they support;
>
> -evaluate the effectiveness of staff support in relation to facilitating community integration for those they support by identifying and assessing the integration outcomes that evolve for the intellectually disabled people being supported.

By setting these objectives, this study has focused specifically on advancing our understanding of how support staff influence community integration outcomes, while the commitment to evaluating the effectiveness of staff in this regard supports the guiding principles of social work research. Although the relative newness of the subject matter makes this study useful in an exploratory sense, the primary intent has been to explain how the actions and attitudes of staff seem to influence the community integration experiences and outcomes of those they support. In a grounded theory approach, the determination of causality is a process of identifying what *conditions* lead to certain *consequences* (Strauss and Corbin, 1994, p. 278).

Operationalising 'community integration'

Developing a study focused on community integration requires one to define what is meant by the concept, and consequently how the presence of community integration will be identified. In Chapter Two, I argued that an evolved definition of community integration was needed if one desired to advance the study of this concept. There are two compelling reasons why an evolved definition of community integration is justified: to dispense with the *either-or* proposition and to avoid the *more is better* assumption.

Dispensing with the 'either-or' proposition

Evidence suggests there is a need for an operational definition which takes account of intellectually disabled people's involvement with *both* their geographic locality and their community of interest, rather than suggesting that community integration is represented by one or the other. It seems clear that within community care for people with intellectual disabilities (and evaluative research particularly), *community integration* as a principle for service has taken on distinct but different meanings, some related to physical integration and some to social integration. Although those studying broad issues related to quality of life may consider both areas, this has not often been the case in more focused studies which fall within the area of community integration. The community psychologist, Seymour Saranson (1974) argues that such dichotomies should be expected, explaining that although there may be agreement on an underlying value (like community integration), this does not ensure that there is equal agreement on what actions are consistent with the value. Like actions, determining the *outcomes* that are consistent with the value may also yield disagreement. This would seem to explain why so many operational

definitions of community integration have sprung up in the literature, despite largely consistent agreement among practitioners and researchers about the value of the principle.

It makes sense then that an evolved definition is needed in order to clarify a precise yet comprehensive meaning for the concept of community integration which acknowledges the importance of *both* physical integration within one's geographic locality and social integration with one's community of interest. Although the definition I put forward in Chapter Two includes reference to both physical and social integration, a truly evolved definition must also take account of the fallacy behind the *more is better* assumption.

Avoiding the 'more is better' assumption

Measuring the *extent* of people's involvement in their geographic communities or their communities of interest, as a way of determining their level of community integration, necessarily establishes a *'more is better'* assumption. While in practice this may seem a reasonable goal, one does run the risk of prescribing lifestyles for people which maximise the extent of their involvement without reference to their own preferences and choices. This approach is hardly any better than that of institutionalisation, which typically prescribed minimised involvement over 200 years ago. Ultimately, both moves deny choice and impose a lifestyle on people with intellectual disabilities, treating them as a homogenous group.

Alternatively, it seems more useful to acknowledge the logical presumption that some people prefer very few relationships and opportunities to get involved while others thrive on a greater number. There are extroverts and introverts, loners and

social butterflies. Some people have very little contact with others, but would describe themselves as integrated in their communities, while other people may be in constant contact with others but feel dissatisfed with their level of community integration. Clearly, the simple extent of involvement is no more a determinant of community integration than measuring how close someone's house in to the centre of town. There is more to the *experience* of community integration than the *extent* of one's involvement in a geographic community or a community of interest. Because these variations in both preference and experience will inevitably exist, it seems that an accurate definition of community integration must take account of what makes one person *feel* integrated while another may not. Such a definition should be concered primarily with the *meaning* of community integration for people, rather than with identifying some set of tangible indicators which when observed, are assumed to confirm integration has been achieved.

A meaning-based definition

In considering what this evolved definition based on meaning might be, two authors present useful theories which facilitated this process. First, Anthony Cohen's theory about the symbolic construction of community is useful to consider when thinking about meaning rather than more concrete indicators to define community integration (Cohen, 1985). This theory suggests that community (an integral concept in any definition of community integration) is best defined by its meaning for individual community members.

> [Cohen's] emphasis on meaning neatly sidesteps the definitional problems posed by the search for a structural model of community as a specific form of social organisation. (p. 9)

Cohen's theory supports the notion that it is meaning which is more important in identifying where community actually exist than more structural evidence. He advises those studying community to:

> ...try to understand 'community' by seeking to capture members' experience of it. Instead of asking what it looks like...we ask what does it appear to mean to its members. (p. 19-20)

If one adopts Cohen's approach to understanding community, and applies it to understanding community integration, it is clear the concept should be defined according to what *being integrated* means for people: the definition should be concerned with what makes people *feel* they are integrated. This notion, that people's community integration is largely dependent on the extent to which they evaluate their lives and conclude they are integrated, can be further refined by considering Sarason's theory of community. In explaining the acute interest in contemporary community which has existed, Sarason notes that:

> What powered the sociology...was a poignant awareness of the depth of modern man's psychological sense of anonymity and alienation. (1974, p. 128)

The way that contemporary community is disintegrating, according to Sarason (1974), is in the psychological sense. Therefore, the challenge of preserving or regenerating community is focusing on the enhancement of people's psychological sense of community: their feeling that they are indeed part of a wider social entity. By applying Sarason's theory to a concept of community integration, preserving or restoring this for people would necessarily involve enhancing the feelings they have which cause them to identify with being integrated.

> ...adapting such focus would require new conceptualizations and tactics; and the major criterion by which these new efforts would be judged was the degree to which they led to a greater psychological sense of community. (1974, p. 155)

The challenge then, to fully define the concept of community integration, is to identify those feelings which both symbolise the achievement of community integration and promote a greater psychological sense of community integration.

An evolved definition of community integration

Having considered these theories and the critical limitations of existing definitions, I set out to define community integration as the feelings that people have which cause them to identify with being integrated. In considering that these feelings would evolve from both one's geographic community and one's community of interest, I defined community integration as an experience with these communities from which an individual derives both:

Feelings of security:	that there are people that care, and who can be turned to for different kinds of assistance; and that because these people are available, one feels secure in coping with the trials of daily life.
Feelings of belonging:	that one feels included and welcome in the geographic community where one lives; and that participation in the community is possible because one feels included and welcome.

There is support in existing literature for these definitions. For example, Whittaker (*et al.* 1983) associates social support networks with providing feelings of security: "enduring patterns of nurturance and contingent reinforcement for coping with life on a day-to-day basis" (p. 55). Sarason (1974) equates a sense of community with a sense of belonging (p. 158). However, critics may raise concerns about the potential for delusion, where one may feel a sense of security and belonging but circumstances then arise which proves these feelings were unjustified. Beyond establishing whether someone has these feelings, the sources of these feelings will

require to be explored to determine the extent to which they appear justified. However, value judgements are involved in concluding whether delusion is preferable to an absence of these feelings, or whether the particular sources of these feelings are indeed desirable. Therefore, there can be no absolute answer to this dilemma.

If however, the logic and rationale underpinning this definition are accepted, then community integration would be determined by the extent to which one feels security and belonging as the result of his/her involvement with a geographic community and community of interest. To evaluate staff effectiveness in promoting community integration for the intellectually disabled people they support, their intentions and interventions would be judged according to the extent to which the outcomes that evolve promote feelings of security and belonging for those they support.

Setting the research questions

The research questions for the study were developed by using the three basic objectives introduced earlier in this chapter, and by taking account of the evolved definition of community integration presented in the previous section. The questions were developed with the expectation that, when used as a basis for choosing a research design and a repertoire of data collection methods, they would enable me to achieve the study's objectives. The research questions evolved from four broad areas I identified that required investigation:

1. Evidence of support for community integration and the definition used in this study.

Research Questions:

How does the agency (that employs the staff) demonstrate support for the concept of community integration, and to what extent is their understanding of community integration consistent with the definition of community integration used in this study?

To what extent do staff believe that developing community integration is an important goal for individuals with intellectual disabilities who move out of institutional settings and into more community-based living opportunities, and to what extent do they agree with the definition of community integration used in this study?

2. Evidence of a recognition that the levels of community integration achieved are less than satisfactory and that there is a need for greater levels of community integration.

Research Questions:

How do staff assess the quality of the networks of relationships that exist for those whom they support, and how do they conclude whether the level of community integration offered through these networks is satisfactory?

How much are the judgements of staff about the quality of these networks of relationships related to personal feelings about how their own networks of relationships contribute to their community integration, or to a belief that the intellectually disabed people they support share with staff, the same need for networks of relationships that offer community integration?

3. Evidence of initiatives undertaken to promote greater levels of community integration.

Research Questions:

To what extent do staff (and the agency that employs them) believe that facilitating the development of relationship networks, which promote community integration for those they support, is part of their role and responsibility?

How do staff identify and carry-out initiatives which are designed to assist those they support to develop and sustain networks of relationships which offer community integration?

What obstacles do staff encounter in trying to assist those they support to develop and sustain networks of relationships which offer community integration, and how do staff deal with these obstacles when they arise?

4. Evidence of the effectiveness of staff intiatives to promote greater levels of community integration.

Research Questions:

What community integration outcomes have been achieved, for the intellectually disabled people being supported, as the result of staff initiatives to promote these outcomes? In particular, how have the staff initiatives affected the extent to which the networks of relationships of those they support offer community integration?

What factors do staff identify as having significant impact on how effective their initiatives to promote community integration ultimately are?

In summary, answering these research questions requires one to investigate and evaluate how staff support people with intellectual disabilities to develop and sustain networks of relationships *which offer* community integration. By this, I mean networks of relationships which offer feelings of security and belonging. By adopting this perspective on community integration, I am making a number of assumptions about how such feelings of security and belonging are linked to one's network of relationships. In this regard, the research questions reflect the assumptions I've made, namely that:

a. the promotion of community integration occurs when networks of relationships are developed *which offer feelings of security and belonging*;

b. different networks of relationships will undoubtedly offer varying levels of feelings of security and belonging; some may offer very little, some very much, some may offer more security than belonging, and still others offer more belonging than security; therefore, the *nature* (not just the size) of someone's network of relationships determines his/her level of community integration;

c. while individual networks of relationships, by virtue of their make-up, will each inevitably offer a some level of community integration, it is also the case that some networks may, by their actions, facilitate the development of greater levels of integration while others may create barriers to this.

Conceptualising community integration in this way and from the outset, enables this research study to avoid the rather limited notion that simply documenting the existence of a relationship network of some kind would signify community integration exists. Clearly, people with intellectual disabilities who have lived in institutional settings were never in the position of experiencing physical isolation whereby they had no network of relationships at all! Yet despite this, evidence suggests their feelings of security and belonging would have been sorely lacking.[8] This reflects an awareness of the importance of *the nature* of people's relationship networks. Essentially then, determining someone's level of community integration involves *evaluating* (not simply documenting) the network of relationships available to a specific person. With this in mind, developing a more sophisticated and accurate way to assess levels of community integration requires one to make the important distinction between relationship networks that are integrating and relationship networks which might well be described as 'dis-integrating'. The research questions in this study are designed to investigate the implications of making this critical distinction.

Part Three: Developing a Research Design

Initial considerations

Although an overarching commitment to theory-building underpins this study, the choices around design were also linked to the problem being studied and the research questions posed in response to these problems. In any study that considers relationship development, there is much emphasis placed on "giving people enough time" so that a realistic picture of relationship development can be obtained. In terms of validity, critics might be highly sceptical of the findings of a study that spent even as long as twelve months with a group of individuals. There is evidence in the existing literature on relocation which suggests both that changes in quality of life are not automatic after a move to a community house, and that there is a strong possibility that changes which do occur may prove unsustainable in the longer term (Emerson & Hatton, 1994). Therefore, I assumed that to generate the most reliable findings on relationship development, I would need to focus on the longer-term development of post-move relationship networks.

In addition to recognising the need for establishing a study of adequate length, I also recognised that studying how relationships develop, and the relevance of these relationships to an individual's life, would be a very complex process. Relationships are inherently social constructs, where people, society, culture, current events and many other things impact upon the process of their development. If one adds to this already complicated scenario, the idea of a third party (staff) in some way directly influencing the development of relationships between those they support and others, the task of understanding how the developments or changes in an individual's network evolved becomes even more complicated. Consequently, I knew I would

have to adopt an approach that utilised a number of data collection methods through which I could undertake an intensive investigation of the subject at hand in order to generate maximum opportunity for understanding.

The Research Design

Keeping in mind the need to adopt an approach which allowed for both length and depth of involvement, I chose a longitudinal design. This design seems particularly suited to developing grounded theory, where "theory evolves during the actual research and it does this through the interplay between analysis and data collection" (Strauss and Corbin, 1994, p. 273). Phased data collection over time offers the opportunity to tranform evolving data into an evolving theory, allowing time for the interplay between data and analysis to be fully undertaken. As well, Hakim (1987) notes that "the longitudinal study is unique in its ability to answer questions about causes and consequences, and hence to provide a base for substantial explanatory theory" (p. 87).

Since a longitudinal study follows people over time, often this approach is also adopted to mitigate against challenges to preserving internal validity. In considering to what extent the evidence in this study demonstrates that staff are likely to influence the community integration outcomes observed, a longitudinal approach to observation, which includes a number of points where data is collected, can improve internal validity. According to Rubin and Babbie (1989):

> One way that studies...can begin to control for alternative explanations, and thereby enhance their internal validity, is by measuring the dependent variable at many points in time. (p. 242)

Longitudinal studies allow one not only to 'infer causal patterns', but also to recognise trends developing among those being studied (Bloom, 1986). A panel study, which involves the same set of people being studied over time, is the form of longitudinal study that has been adopted here. According to Bloom:

> With the panel, not only can we make some descriptive statements about the group averages over time, but we can also look at the patterns of changes in particular individuals. These patterns may indicate some common causal factors as well. (p. 51)

The panel approach used in this study included data collection at a number of separate, post-move points. (Details of the pattern of data collection can be found in Chapter Five.) This emphasis on post move data collection was chosen because it would enable me to document outcomes concerning relationship development and community integration in the longer-term: a central yet largely unaddressed issue within previous studies concerned primarily with transition outcomes.

Participants in the study and the focus of analysis

Given the need to undertake a study which required both long and intense involvement with those being observed, I chose to identify a comparably small number of participants. Longitudinal studies, "because of the costs and complexity of following people over time and space...generally use smaller samples than cross-sectional research" (Bloom, 1986, p. 50). In addition, identifying a small number of cases is a typical approach when the aim of the research is inductive theory-building (Grinnell, 1988). Participants in this study were of two types: adults with intellectual disabilities and the staff members who support them. The method for selecting these participants is described below.

As a starting poing, seven adults with intellectual disabilities were identified. The process of selecting these seven individuals largely relied on non-probability sampling since I had neither the time or resources to define and sample the entire population of people with intellectual disabilities moving out of institutional settings in Scotland. I was however, able to identify a local and accessible subset of this population that appeared to be typical. Again, in the absence of adequate time and resources, I had no way to make a grounded determination that this subset was indeed typical. I relied instead on my own knowledge as a practitioner to come to this conclusion. I selected the subset (a hostel population of 18) primarily because it fitted the central parameter of my study: being made up of adults with intellectual disabilities in the process of moving from an institutional living setting to a community-based living setting. I also selected this subset because of my familiarity with the group and the agency supporting them. This familiarity meant I could arrange access and consent quite easily and thereby quickly begin collecting pre-move data to allow for maximum time to be spent studying their post-move experiences. (Access and consent issues are discussed in Chapter Five.)

From this hostel subset, I undertook purposive non-probability sampling (based on my own knowledge of this subset) to select seven typical cases for study. Rubin and Babbie (1989) explain that purposive, non-probability sampling of a subset of a wider population can be used when time and resource issues would preclude one from studying the entire identified subset (p. 229). The seven individuals were identified, from my own knowledge and in consultation with staff, as typical of the wider group of eighteen who made up the entire subset. These individuals were deemed typical for a number of reasons. All had spent a significant number of years in institutional care. All attended an adult training centre at the time of the move. In terms of ability, they all had in common an assessed need for twenty-four

hour support, which included sleep-in staff. It is worth noting here, for comparison sake, that at the time of selection, all seven were mobile in that they were capable of walking, although two had to rely on a wheelchair for longer journeys.

Collectively, these seven individuals were transitioning from the hostel to two community-based residential projects, each having its own staff team. Within this process, both the hostel and the community-based projects being set up were supported by the same organisation. The two staff teams supporting these seven individuals formed the second group of key participants in the study. They were selected by virture of their connection to the group of seven identified above. No other parameters were applied. It is important to stress here that because the objectives of the study are to investigate the attitudes and actions of staff in relation to the community integration outcomes which evolve for those they support, the primary focus of analysis in this study was intended to be the fourteen individual staff members who collectively made up the two teams.

Although the study was always intended to look intensely at a small sample of individual cases, I chose to identify seven adults with intellectual disabilities, as opposed to an even smaller number, so that an opportunity would exist for trends and patterns to develop (particularly between the two staff teams) , and so that there would be some allowance for attrition built in from the start. In addition, my selection of seven individuals who together made up two *projects*, rather than the selection of seven individuals from seven different projects, was done to create a manageable workload for the data collection period. Since most individuals with intellectual disabilities are supported by a team of staff (rather than one person), I recognised that I would need to investigate and evaluate *each member of that team* in order to be able to achieve the fundamental intentions of the study. Investigating

and evaluating seven teams of staff (particularly conducting individual interviews with every member of these teams) would have taken far longer than the time period I had available to me to carry out my data collection. By selecting seven individuals who collectively were supported by two teams, the workload was one that I felt could be successfully managed.

Cautions related to the choice of research design

Two particular criticisms may arise over the choice of research design and participants outlined above. These involve the size of the sample and the corresponding potential of the study's findings to be viewed as generalisable. Both of these issues must therefore be addressed.

Issues of sample size

Classic introductory research methods textbooks often begin with a discussion of the rigors required to produce legitimate research. Within this, an emphasis on utilising large samples can usually be found. In defense of more flexible interpretations of legitimate sample size, Wellman (1977) states that the adequacy of a sample size is really a function of the questions being researched, rather than any predetermined criteria. In the field of social work particularly, where the profession's knowledge base is traditionally derived from practitioner wisdom, the major contribution that research can make is generally agreed to be through the systematic study of practice. Consequently, it is often assumed that "the research agenda should be developed around a set of research issues directly relevant to persons at critical points of professional decision-making" (Austin, 1979). Therefore, research questions for

social work are typically focused upon situation-specific professional decision-making. By situation-specific I mean decision-making which occurs in individual cases and in the unique context each case brings. In recognising this, one can legitimately conclude that social work research allows for, and quite possibly necessitates, smaller sample sizes in order to generate valid findings.

Despite these seemingly convincing arguments in favour of small sample size, some writings on social work research suggest sample sizes of at least 30, while citing conventional wisdom at 100 (Grinnell, 1988). However, more recent trends indicate that achieving an impressive sample size has become less important. A study by Reid & Harrahan (1981), which looked at patterns in pre-1973 and post-1973 social work research, found that, in post-1973 research, studies with a sample size of 100+ declined by over 40% from pre-1973 figures. While this may have been due, at least in part to financial constraints, there is also evidence that post-1973 research placed greater emphasis on observation than on traditional questionnaires or standardised tests (Reid & Hanrahan, 1981). Therefore, it would seem logical that this type of data collection took more time to do and consequently, the sample size may have been reduced in favour of what is now considered to be a valuable form of data. According to Bloom (1986):

> ...all research is a compromise on ways of obtaining information as the basis for forming inferences on how and why people behave as they do, think as they do, and feel as they do. Whether we obtain a large amount of information on one person or a small amount on many people, at one time or over time, is a matter of logistics. Each approach has its benefits and its costs. (p. 51)

Perhaps the most significant cost of doing a study involving a small sample is that of external validity.

Issues of external validity

The use of non-probability sampling in this study, though quite common in social work research and evaluation, is not thought to lend itself to generalisability (Grinnell, 1988). In fact, all non-probability sampling is typically described as a "last resort" to be used only when probability sampling is not feasible. However, because social work research is typically focused on the effectiveness of individual interventions, this may explain why generalisability has received little attention and non-probability sampling is readily accepted.

Although developing a study which involves seven individuals and two teams of staff is not as great a threat to external validity as a single case study approach, the use of such a small sample raises some issues regarding generalisability of the study's findings. Despite support among a wide range of researchers for the legitimacy of small scale studies, their findings are rarely convincing when it comes to traditional notions of generalisability. This is where the alternative view of generalisation, advocated by those who subscribe to a grounded theory approach, becomes particularly relevant to a study aimed at theory generation.

According to Vaughan (1992), theory (or analytic) generalisation should be the goal, rather than a more traditional quest for statistical generalisation. Vaughan calls this process 'theory elaboration', where theory is generated and then its generalisability is considered by elaborating and modifying it as incoming data are meticulously played against the original theory. Consequently, it seems that adopting a commitment to theory generalisation, rather than statistical generalisation, would strengthen this study's ability to maximise external validity.

Yet theory generalisation is not without its own weaknesses. If we accept that science is a social construct, then we must also accept that different researchers will theorise about particular data in different ways. A particular researcher will theorise, based on the data collected, in a way that is naturally influenced by his or her values, attitudes, and beliefs. This will almost invariably result in substantively different conclusions being reached about a similar set of data. Consequently, truth would seem to be the intersection of a number of researcher's conclusions on the same set of raw data. In the end, it seems "our truth is the intersection of independent lies."[9]

Summary

Having considered fully the merits of a longitudinal design, and resolved my position on the debates over legitimate sample size and preserving external validity, I concluded that sufficient justification existed for pursuing the design and sample proposed, given the objectives this study set out to achieve. Although the reader may expect that I would now move on to discuss the particular data collection instruments used in this study, it is important to explain here however, that the implementation of the research design in this study was not a straightforward process. Circumstances outwith my control led to a change in the original participants of the study, which ultimately affected the implementation of the design. Although the longitudinal design was not abandoned, the circumstances which occurred did alter the outcomes of the data collection period, and consequently, the conclusions presented in this thesis. Therefore, the circumstances that evolved, along with the way in which they affected the study, are discussed in

the final part of this chapter. The data collection methods are then introduced in Chapter Five, along with the approach used for data analysis.

Part Four: Issues arise in implementation

> As most researchers know, but seldom state publicly, the linear, narrative way in which research is presented is very rarely matched by the research act itself...The research act occurs mainly in the process of inquiry. Sometimes this process is straightforward and linear. I suspect however, that often it is not. (Wellman, 1977, p.47)

Problems develop that infringe upon the original plan of investigation

The process of data collection with the seven individuals and two staff teams identified was to be carried out concurrently to allow for maximum length of involvement with these groups and to enable me to identify trends and patterns among the participants more clearly and easily. More to the point, these individuals were due to make their moves to community houses at the same time which actually necessitated concurrent data collection to ensure that the set points at which my post-move interventions were to occur remained consistent for all of the individuals being studied. While the first three individuals, and the staff team which supported them, made the move as planned (and I was able to begin post-move data collection on schedule), the other four individuals and their respective staff team were delayed six months in moving to their community house. Although this did not in and of itself make this group unfeasible to work with, I found that when my post-move involvement was due to commence with this group (at four months post-move), the staff team faced severe sickness and two resignations. This left them unable to

allocate protected time for interviewing individual staff members: the *central* component of my data collection methods.

At this point, I made the decision to wait five months (until the second post-move intervention point) to see if these problems rectified themselves. If things went ahead at that stage, I recognised I would still have three data collection points available and in common with the first group. After five months however, there was little change in the availability of time to interview these staff, and the new project leader could not guarantee the staff would have time to assist those they supported to fill out diaries - also a key data collection method. Consequently, I decided that proceeding with this group had become unfeasible. I felt that the uncertainty surrounding my ability to carry out the two, key forms of data collection would render my involvement insufficient to achieve the study's objectives and to gather data which would adequately address the research questions.

I chose not to seek out other individuals supported by the same organisation since all who were due to move out of institutional settings at that time had done so and I would have had no opportunity to collect pre-move data with these people. At this point, I felt my best option was to take a one-year suspension and attempt to locate another small group of individuals who were moving out of an institutional setting into community-based housing. During the suspension period, I found a replacement group due to move out of a hospital in east-central Scotland. This group, and the hospital staff and management supporting them, as well as their community-based counterparts, were all willing to become involved in my research. I proceeded to undertake a period of pre-move data collection, like that done with the first group of individuals involved in my study. Again however, these people's move was delayed and delayed considerably - by nearly nine months in the end. I

waited some six months after collecting the pre-move data before deciding that my plans for this group of individuals had also become unfeasible. My decision was largely due to the fact that at that point, it was unclear when the move would actually happen (and in some ways, whether it would happen at all in the foreseeable future). I recognised that waiting any longer may well have been in vain. In addition, this delay on top of previous delays left me very limited time for post-move data collection before the point at which I really needed to begin to analyse my data and write up my findings. There was certainly no opportunity to conduct an even 12 month post-move study with this second group. This hardly compared with the first group where by this time, I was just completing a twenty-seven month post-move data collection period. This combination of circumstances raised serious questions for me with regard to the way forward for my study.

Strengthening the study despite the unexpected problems which arose

The stage I had reached left me with two distinct options. The first was to discontinue attempts to replace the lost participants in the study and focus exclusively on the three adults with intellectual disabilities and their staff team. Although not without merits, this option raised serious concerns for me with regard to external validity that I could not comfortably resolve, even when working from a concept of theory generalisation. I recognised that even in case study research, a multiple case strategy is typically preferred because it is seen as more compelling and robust than single-case designs (Herriot & Firestone, 1983). Multiple case study designs are founded on the need for replication among a group of cases to generate convincing support for the initial propositions put forward (Yin, 1994). In

this study, I applied the same stipulations for theory generalisation and concluded that the most productive option would be for me to attempt to test the conclusions evolving from the first group to see if they were indeed replicated with other groups. While circumstances left me particularly well-placed to do this, since the data collection with the first group was finished and conclusions were already clearly evolving which I could test, I also recognised that the choice between inductive and deductive approaches to research does not have to be an entirely either-or proposition. According to Wallace (1971), research is a cyclical process, involving both inductive and deductive approaches. One can develop theories through inductive investigation of particular instances, and can then apply that theory to a particular case and undertake a study utilising deductive logic.

Consequently, I remained committed to the same longitudinal design and data collection methods, but due to time constraints, was forced to consolidate the process of investigation used with the first group to accomplish two post-move interventions. To contrast this loss of depth with greater potential for breadth, and the greater potential to adequately test the generalisability of my initial conclusions, I sought a number of individuals and staff, who collectively came from a variety of projects sponsored by a number of provider organisations. I located and gained consent from eight adults with intellectual disabilities, and a member of staff connected with each of these individuals. Collectively, they came from four community-based residential projects sponsored by four different organisations.

These 'secondary' participants were selected in ways consistent with the first group. The intellectually disabled people had an assessed need for 24 hour support. As far as possible, I also sought particular intellectually disabled individuals who fell within the same general age and ability range as those from the primary sample.

The eight individuals ranged in age from 31 - 58: an age range consistent with the primary sample. They were all similarly mobile: none were largely reliant on the use of wheelchairs. There was a range of communication ability which was greater than that of the primary sample, but which balanced out overall. Some people were very able to communicate effectively, while others demonstrated varying degrees of ability in relation to comprehension and expression. This wider range of communication ability was felt to offer enhanced opportunities to consider the extent to which environmental factors that effect community integration outcomes are universally relevant, despite differences in the more intrinsic factors of particular individuals. They had come to live in group-home type settings by moving from their parents homes {2} or from long-stay hospitals {6}. They had lived in these community-based projects for varying lengths of time, ranging from 2 1/2 years to 3 1/2 years when data collection began. Finally, the size of the homes in which people resided did not vary significantly from that of the first group, although the wider projects they belonged to did. For example, tenants in one project lived in a 'satellite' flat for three people attached to hostel-type accommodation where nine people lived. Another project had tenants living in 'dispersed' two-bedded flats where some twelve flats formed a series of semi-detached buildings. Finally, two projects were single group homes housing four people each. Again, these differences were thought to offer a useful way of determining whether my conclusions regarding staff's impact were universal, despite varied housing models.

Due to time constraints, I was forced to select only a sample of each of the staff teams from the four projects identified, I sought in the first instance the keyworkers for each of the identified intellectually disabled adults. Where a keyworker was not available, the longest-serving staff member was recruited since his/her knowledge of the individual, his/her relationship network, the local community, and the

sponsoring organisation were thought to be the most well developed. In the end, eight staff were asked and agreed to participate in this part of the overall study.

Chapter Conclusion

This study's emphasis, upon developing a theory about residential support staff's impact on the community integration outcomes of those they supported, was designed to address what appeared to be an important yet largely unexplored issue within community care for people with intellectual disabilities. By beginning with an evolved definition of community integration, I believe I have enhanced this study's potential to get to the heart of a complicated subject, the nature and meaning of which many community care provider organisations seem to struggle with. The adoption of a longitudinal design enabled this study to move beyond the outcomes of transition, thereby addressing more longer-term outcomes and the explanations related to these. As well, important patterns connecting staff attitudes and actions to the tangible community integration outcomes which evolved for those they supported could be identified through this design and subsequently used to inform the process of theory-building.

Yet despite these good intentions, the unexpected pattern of events that evolved during the data collection period forced me to reconsider what had been a straightforward, classic form of longitudinal study. Rather than choosing to base my study solely on the first group, I attempted to add a manageable and time-limited investigation, designed to strengthen the results of what had already been accomplished. The use of the secondary samples enabled issues of generalisability

to be addressed *within* the same study. On the basis of the various rationales presented in this chapter, I went forward with a study which involved a two-pronged, inductive theory-building and deductive theory-testing effort, albeit one that remained small-scale and longitudinally-oriented.

[1] Quoted in Cheetham *(et al.* 1992) p. 33.

[2] Wimsatt quoted in Heineman (1981) p. 388.

[3] William Ryan (1984) first coined the phrase blaming the victim.

[4] Although research based on individual pathology is not necessarily invalid, adopting such a perspective in the field of social work might be likely to be considered inappropriate if an ecological approach to understanding the client's situation is emphasised by practitioners.

[5] Schalock & Kiernan (1990).

[6] Schwartz (1992); Richardson & Ritchie (1989); Atkinson & Ward (1987); Day (1988).

[7] Other research in social work, that has looked at the need to get beyond intentions to outcomes in determining the effectiveness of social work intervention, includes Challis & Davies (1986), Davies & Knapp (1988), and Challis *(et al.* 1989 & 1990).

[8] Studies by Jack Tizard and Pauline Morris cited in the bibliography strongly suggest this to be the case.

[9] Levins quoted in Wimsatt (1980) p. 251. Quote appears in Heineman, (1981).

CHAPTER FIVE

"Data Collection & Analysis Methodology"

Chapter Overview

This chapter serves three key purposes:

1. To describe the access and consent process used with the participants in the study;
2. To explain the data collection methods used; and
3. To outline the approach used for analysing the data collected.

The bulk of the chapter is devoted to introducing the six data collection methods: relationship network mapping; interviews; personal diaries; staff meeting observation; a Likert scale; and agency documents. The rationale, design and application, as well as the advantages and limitations of each method is explained in detail. How these methods interface, to offer a comprehensive set of data from which to draw conclusions is also discussed.

Despite the changes in the study participants outlined in the previous chapter, this research retained its original methodological choices, designed to facilitate a study which would involve both intensive investigation and a unique focus on staff.

Consequently, the data collection methods originally chosen remained valid and relevant.

For clarification, 'the primary sample' referred to in this chapter represents the three intellectually disabled individuals and their staff team who were originally recruited to participate, and on which the provisional theory developed in this thesis has been based. The four 'secondary samples' are the four projects, collectively including the eight intellectually disabled adults and eight corresponding support staff, who were recruited after the loss of the original second sample, and were subsequently used to test, albeit in a limited way, the provisional theory developed with the primary sample.

Part One: Access and consent issues

The primary sample

The agency which sponsored the primary sample was (at the time this project was set up) a newly established private, not-for-profit organisation whose development was initiated by co-operation between the district social work and health providers. This agency was intended to manage the resettlement of all people with intellectual disabilities who were at that time, living in institutional care in the district. In response to this remit, the agency had developed a number of projects to offer community-based living options to people moving out of two hostels and one hospital unit. The agency's maiden initiative was the closure of the hostel from which the three people with intellectual disabilities at the centre of this study came.

Therefore, the community-based project which constitutes the primary sample in this study was set up at a time when the sponsoring organisation was in its relative infancy. Now nine years on, it has grown dramatically, and seen a six-fold increase in the number of people with intellectual disabilities that it supports.

Obtaining access from the agency was a uniquely straightforward process because I had worked within the hostel for fourteen of the nineteen months preceding the men's move to the community-based project in question. Consequently, I knew the intellectually disabled people, the staff, and the organisation well. My paid relationship with the men and their staff team ceased prior to their move out of the hostel, although I continued to work for the agency (in a hospital it managed) for a further eighteen months. Therefore, my roles as immediate staff member and researcher overlapped only during the arranging of consent and the pre-move data collection period.

The seven individuals with intellectual disabilities who were originally asked to participate were approached for consent on two occasions, first by myself, and then by a member of their staff team who 'double checked' their willingness to participate. Because I knew these individuals, they demonstrated a willingness which was probably enhanced by their familiarity with me, and the extent to which this made them feel they could trust me. Ultimately, only three individuals from this first group remained participants in the study, due to the problems explained in Chapter Four. These three individuals were men, between the ages of 35 and 55, who moved from the hostel to live in two neighbouring flats (one single, one double) in a small town located in the same district as the hostel from which they moved.

The two staff teams originally approached to participate were somewhat unique in that they were recruited within the year preceding the intellectually disabled adults' move from the hostel, and therefore, spent their first year working alongside these people in the hostel setting. Obtaining consent from these teams was done via the staff meetings within the hostel, where the research and their role in it was explained. They were given time to think about participating and all consequently agreed. Again, staff's willingness to participate may have been related to their familiarity with me, and the fact that I was still a member of the wider hostel team at the time, albeit in a development role.

There was a significant level of consistency in the staff team that remained involved in the research throughout the three-year data collection period: during this time, there were only two changes in this staff team of six. While one could argue that this was not typical and consequently, the findings would not be statistically generalisable to other staff teams, such continuity proved to be a significant strength to a study designed specifically around exploring the pattern of staff attitudes and actions over time as they related to the community integration outcomes for those they supported. On the two occasions when staff did leave, the two new members of staff were asked to participate through the same process used with the original group.

The four secondary samples

Due to the unforeseen circumstances which led to the recruitment of these secondary samples, and the inevitable time delays this caused, requests for participation were done more quickly for these samples. Letters were sent out to five Scottish agencies

which were known to this researcher to provide community care for adults with learning difficulties. All were significant providers of community care, identified themselves as voluntary organisations, and were well established at the time they were approached.

In response to the initial letters, four agencies each nominated a project for the study. The projects collectively spanned the eastern side of Scotland from Grampian to Lothian. This provided another useful way to determine whether the findings and theories generated by the primary sample were indeed generalisable - in this case, to other places within Scotland. I made visits to each project to explain the research and identify willing participants (both staff and people with intellectual disabilities). A consent process, largely consistent with that used in the primary sample, was followed for all of the secondary samples. The eight individuals with intellectual disabilities who were approached seemed, like the first group, keen to become involved in the project. Although some were more shy and reserved because they did not know me, they were all willing to become involved and the 'confirming of consent' process undertaken by staff reinforced this. The organisations' response to the request for access was overwhelmingly positive, and this response appeared to be directly related to the time-limited nature of the data collection period proposed, and the small number of staff hours required.

Unlike the primary sample, each of the eight staff who participated were asked, on an individual basis, to become involved. Consequently, all self-selected to some extent, which may have influenced the data because they were predisposed to participating or to the topic of the research study. They may not, therefore, be representative of the wider project teams from which they came. As part two of this

chapter will demonstrate, participation involved entertaining a number of data collection methods.

Participant control during the research

Since interviews were the primary form of data collection used in this study, a mechanism to give participants control over their involvement was built into this data collection method. Every participant interviewed was asked to signed a 'consent form related to tape-recording *after* each interview. This enabled them to control the extent of their participation *during* the research, by giving them the option to retain the tape made, rather than release it to me. No one ever refused to allow me to retain a taped interview, and this seemed to offer confirmation of their continued willingness to be involved in the research.

Part Two: Data collection methodology

Introduction

According to Wellman (1977), methodological discussions are, in their most basic form, a claim to credibility. If the researcher's methods are suspect, so then are the findings. In this section, the six methodological choices for the study are introduced, with attention to the essential considerations which underpinned these choices. At the most basic level, choices related to methodology inevitably intersect

with the on-going debate over the value of qualitative versus quantitative approaches to data collection.

Determining a stance on the qualitative-quantitative debate

Despite the endless paper trail which documents the many arguments put forward in relation to this debate, resolution remains unachieved. According to Duffy (1985), the need to debate these issues should generate better research since scholars are consequently forced to face and address the controversies involved. Given the probability that the controversies are unlikely to disappear altogether, there does seem to be some light at the end of the tunnel developing in the literature of nursing studies. Recent writing in nursing research suggests that the most laudable goal is the achievement of balance. Duffy (1985) suggests that grounded theory should be used to develop 'reality-based nursing theory' which can then be verified by true experiments (p. 231). By asserting this way forward, Duffy extols the merits of both qualitative and quantitative approaches, although she delineates specific purposes for each in the process of investigation and the generation of new knowledge.

Corner (1991), another writer from the field of nursing studies, argues for triangulation of methods and types of data, which would include both qualitative and quantitative approaches to data collection. Unlike Duffy, Corner is more specific in arguing for the use of both qualitative and quantitative research methods in the same study, and claims this approach "can provide a richer and deeper understanding of the area under investigation than would otherwise be possible" (p. 718). It has been on this basis that a decision was taken to use both qualitative and

quantitative forms of data collection in this study. However, since scope for achieving a perfect balance between qualitative and quantitative methods is certainly limited in any case, this study has been slanted toward qualitative methodology for three reasons.

First, qualitative data collection is generally considered to be more relevant for subjects which have not been previously researched (Stern, 1980), making it particularly suited to the subject of this study. Second, qualitative method is also assumed to be a fundamental pre-requisite for research which sets out to avoid victim-blaming assumptions (Barnes, 1992): a premise also at the core of this study's development. Third, and most important, the decision to slant the balance toward qualitative methodology was directly connected to the adoption of a fieldwork approach for data collection.

Adopting a fieldwork approach in data collection

Studies based on inductive theory-building and a grounded approach often involve field research since it is a particularly effective way to develop general theories from the investigation of the particular. The process of fieldwork typically contributes directly to the development of theory as experiences of the field and data collected influence the way the theory evolves over time (Rubin & Babbie, 1989). In addition, fieldwork is particularly useful when using a longitudinal design.

The use of field methodology is generally intended to advance inquiry into some social process in its own natural context (Schatzman & Strauss, 1973). According to Lofland (1971), topics appropriate to fieldwork include the study of encounters

between people, roles that people occupy, and relationship patterns between people. All of these are central aspects of this study. Further, according to Rubin and Babbie (1989), what is particularly valuable about field research is the comprehensiveness of perspective it gives the researcher, and the potential it has to address research topics that defy simple quantification. This study's focus upon staff attitudes and actions, and the correlation between this and changes in the relationship networks of the people with intellectual disabilities they support, seems an excellent example of a topic which defies simple quantification.

The connection between fieldwork and qualitative methodology

Fieldwork has a number of common threads with qualitative method. Qualitative method and fieldwork share a common concern with meaning rather than numbers (Schatzman & Strauss, 1973). A qualitatively-driven approach to fieldwork was developed in this study in part because the *exploration* of the *experience* of community integration was judged to be a more productive mode of inquiry than mere quantification of observable integration outcomes. Qualitative method is associated with documenting in great detail the nature of the subject being studied. Through this, the qualitative researcher is thought to be able to explain the complexities of social phenomena, which includes the experiences of human beings. According to Lofland (1971):

> The strong suit of the qualitative researcher is his ability to provide an orderly presentation of rich, descriptive detail. He can move close to a social setting and bring back an accurate picture of patterns and phenomenological reality as they are experienced by human beings in social capacities. He can discover, document, and render patterns of social action, and make the participants of a social setting live for us as human beings. (p. 59)

Davis (1961) used qualitative method and field research to explore the phases through which a sociable relationship between a non-disabled and a visibly disabled person may typically pass. As well, more recent studies by Bayley (1997), Atkinson & Ward (1987), and Richardson and Ritchie (1989), which focus on the relationships of people with learning difficulties, have also relied upon largely qualitative fieldwork methods.

Choosing particular data collection methods in fieldwork

While it may seem justifiable to simply pursue data collection methods which share a common connection with both fieldwork and qualitative method, Schatzman and Strauss (1973) argue that the field researcher sees the choice of method for data collection largely as a system "for getting answers to certain questions about events that interest him [or her]" (p. 7). In field research, specific methodological choices are weighed up against the range of choices, and the strengths and weaknesses of each is considered. Ultimately, the decision about a particular method's adequacy is a function of whether it is logically consistent with the questions being asked, whether the data produced from such a method addresses the questions posed, and whether the method can be adapted to the characteristics and context of the object of study (Schatzman & Strauss, 1973).

Data required to address the research questions posed

According to Stake (1995), "what one does in the field needs to be guided by the research questions" (p. 50). As well as the gathering of data, this includes choosing

data collection methods and developing the specific tools which will be used. Given the previously presented research objectives and questions, it is assumed that data is required across the following broad areas:

> *The nature of the lifestyles of the people with intellectual disabilities involved in this study.
>
> *The nature of the relationship networks of the people with intellectual disabilities involved in this study, including changes over time in these networks.
>
> *The role of staff and how it is conceptualised by the individual staff and sponsoring organisations involved in this research.
>
> *The attitudes of staff, in particular the attitudes they hold in relation to people with learning difficulties and their relationship networks.
>
> *The activities and actions of staff, both as a group and as individuals.
>
> *The aims of the sponsoring organisation, particularly in relation to community integration, and how these aims are operationalised.

It is worth noting here that individual methodological tools employed for data collection in this study often enabled data to be collected across a number of the areas listed above. The purpose and rationale behind each of the methodological tools chosen, and the way these tools have been designed and applied, is discussed in the next section.

Data Collection Tools

1. Relationship Network Mapping

Rationale

Research that focused on relationships between people, or on exploring the relationship networks of particular individuals, provided a useful framework for developing this aspect of the data collection. Seed (1990) demonstrates well the benefits of using relationship network analysis in social work, and describes this approach as enabling helping professionals to understand and enhance a client's network of informal support. However, although Seed argues in favour of applying sociological notions which would help one define specific qualities of particular relationships like 'affective' or 'instrumental' (p. 42-6), he does not suggest that within social networks, people can be systematically classified. Seed appears to apply terms like friend rather loosely. He does not take the position adopted here which assumes that if such classification were done in a systematic way, this could usefully illustrate differences in the relational qualities which Seed considers important. For example, if someone were classified as a friend rather than a social acquaintance, this would imply a relationship of higher quality and greater significance than that of a social acquaintance. Similarly, if someone categorised as a friend previously, is now identified as a social acquaintance, this would suggest a declining role and regard for that individual.

In this study, it was felt that in order to assess the quality of a particular relationship network, and more specifically, to identify changes in the quality and significance of

particular relationships within that network, it would be essential to be able to classify different types of relationships in some consistent way.

Design and application

Existing literature in sociology and psychology that deals with the study of relationships, often relies on firm definitions of relationship categories in order to assess notions of relational quality - particularly in non-kin relationships. Davis and Todd (1985) have developed a *paradigm case formulation* of friendship which they describe as 'a genuine, complete example which would also be an archetypal case - one by reference to which other cases will be understood to be examples of the same sort' (p. 19). Their consequent empirical study validated the use of the paradigm case to distinguish among various non-kinship relationships. This 'complete' example formed the basis for the prototypes of intimate friend, friend, and social acquaintance developed for this study. {See Appendix, p. 434, which includes the paradigm case formulation and the set of prototypes developed for this study.}

Given that the paradigm case could be considered an 'ideal' example of a non-kin relationship, the descriptors utilised by Davis and Todd were directly translated into the intimate friend prototype for this study. The friend and social acquaintance prototypes were then developed to represent increasingly 'diluted' versions of the intimate friend prototype. Overall, five prototype categories which were assumed to represent the various types of adult relationships one might have, were developed for use in documenting the relationship networks of the people with intellectual disabilities involved in this study. The five prototypes - intimate friend, friend, social acquaintance, adult relative, and professional - were then assembled into a

relationship network template, which was filled in from information gained in staff interviews. {See Appendix, p. 439, for an example of the relationship network template used.}

While the intention behind developing the prototypes was to enable staff to identify the category to which a particular individual belonged, staff's ability to make such precise distinctions were likely to be hampered in some cases by the extent of their knowledge about the nature of particular relationships. However, in considering the range of people who belonged somewhere in the network, staff were able to use the prototype definitions, not only to determine the classification of specific relationships where their knowledge would allow this, but also to then place other individuals into the network according to their ***relative*** significance to other members of the network. Although this would accurately imply that a continuum was intended to exist between the categories of intimate friend, friend, and social acquaintance, it was not the case that this approach then necessarily required staff to place people in all of these categories. This was proven by the fact that for a number of the intellectually disabled individuals studied, the intimate friend category remained empty. Therefore, the prototypes invited a mix of considerations, relating both to precise classifications where possible, and to notions of relativity between various relationships within a particular network. Together, these two approaches to formulating an individual's relationship network were thought to provide a systematic way for staff to convey their perceptions of the relationship networks that existed for those they supported.

Advantages of approach

The combination of these relationship prototypes and the network template enabled this researcher to establish the content of a particular individual's relationship network through discussion in staff interviews. People involved in the tenant's life could be categorised, enabling the balance of relationships in a tenants network to be quantified. By updating and revising these networks four times in the primary sample and once in the secondary samples, changes in the network could be observed: in particular, changes in the status of particular individuals in the network could be evidenced by comparing the networks which were longitudinally collected during the staff interviews. The networks revealed both additions and losses, as well as promotions and demotions in the intensity and significance of non-kin relationships (intimate friend; friend; and social acquaintance). This approach provided a valuable degree of detail about the exact nature of relationship network changes, which could then be discussed in the remainder of the interview.

Cautions and considerations

There are however, drawbacks to establishing the relationship networks in this way for the intellectually disabled people involved in this research. The networks are based purely on staff perceptions. Emerson and Hatton (1994) note that:

> ...evaluating change on the basis of information gained from care staff runs the risk that any changes may simply reflect changes in informant attitudes or expectations rather than actual changes... (p. 36)

This was improved in the primary sample, by asking two staff members to help devise a particular tenant's relationship network over time, generating two perceptions of the relationship network of a particular individual at a particular time.

However, in the secondary samples, due to time constraints, this was not possible and just one staff member helped devise the relationship networks for a particular individual. Staff in the secondary samples were however, often those with a number of years service who had relatively extensive knowledge of the tenants in question.

Ultimately, however, the networks remain based on staff perceptions. Though some may criticise such an approach, this was done for a particular reason. The decision to rely on staff perceptions in devising relationship networks was based on the assumption that what staff think or perceive about a tenant's relationship network is significant when attempting to study the actions of staff in relation to changes in this network. It is argued that if anyone's perceptions about a network should be sought, it should be that of staff, since the focus of the study is on how and why they act in ways that influence that relationship network. For example, if a staff member perceives a particular tenant's network as being of high quality, and evidence suggests that this staff member spent the majority of time assisting the tenant to maintain, rather than build, the network, their perceptions would legitimise their actions. Whereas if a staff member is highly critical of the value and quality of a particular tenant's network, and evidence suggests this staff member spent the majority of time assisting the tenant to maintain, rather than build the network, such a finding would raise concern and merit further investigation. Clearly, staff attitudes and observations about the quality of tenants' networks must be taken into account when attempting to explain why staff do what they do. Therefore, the choice was made to look at the relationship networks of tenants from the perspective of staff, since it is staff with whom this study is concerned.

Yet in some ways, the placing of particular people into particular prototype categories was not purely subjective, given that staff were provided with prototype definitions and asked to use these as guidelines in placing particular people in particular categories. This is less subjective than simply asking who someone's friends are in an open-ended, non-specific way. Not only would this involve subjective judgements about the nature of particular relationships, but also equally subjective judgements about what 'friend' means. The use of prototypes ensured that the label applied to a particular relationship was at least based on a consistent understanding of what that label represented.

Further concerns may be raised about the extent to which staff could, in an interview situation, recall adequately who all constituted the relationship network of a particular individual. The structure of this portion of each interview took account of this concern. When staff were asked to identify the various people who made up a particular tenant's network, attention was paid to the fact that people, places, and activities often inter-relate. According to Seed (1990):

> Sometimes a place is important, like a building where a club is held. A building can be important because it is the place where the client meets new people and engages in new activities. Sometimes people are important only in the context of a particular activity or, sometimes, they are important regardless of the activity - or the place. (p. 11)

Staff were asked to identify the various places where the individual spent his/her time and the various activities he/she was involved in. This then sparked insight into the variety of people who might be part of that person's relationship network. It is assumed that if one considers all of the places a person spends his/her time, and all of the activities a person participates in, this is likely to be a thorough basis for determining who the person spends his/her time with, and consequently, who makes up his/her relationship network.

In addition, particular discussion took place about the people who were placed in each category of the relationship network. This was particularly useful in the case of adult relatives, since some people proved to have very limited contact with their relatives, while others were much more regularly involved.

One other possible drawback of having staff generate a list of people who constitute a particular individual's relationship network, is that this person might have a relationship with someone whom the staff are not aware of. To minimise this possibility, diaries of the individual's daily lifestyles (explained later in this chapter) were used as an additional source of information on relationships. This included not only people who were met face-to-face in daily life, but also people with whom the individual had contact either by phone or post. Any people mentioned in the diaries, who were not listed in the relationship network that staff generated, were offered when the network was updated, and these people were added to the network in the prototype category staff assigned. If staff did not know who particular people were, these people were mentioned in interviews with the individual to clarify their significance to the person. Indeed, it rarely proved the case that staff did not know who these people were, but rather had difficulty associating names (particularly when only a first name was provided in the diaries).

2. Interviews

Overview

Interviews were by far, the data collection tool most relied upon in this research study. Interview questionnaires were generally semi-structured and developed over the course of the fieldwork in response to what previous experience with the primary case brought to the attention of the researcher. This is typical of both a grounded theory approach and the fieldwork process, where understanding of the issues involved in the research questions being studied evolves throughout the process of data collection. Each phase of fieldwork, and the data collected from it, is reviewed and the results of this review guide the subsequent exploration of the main research questions.

Interviews were conducted with project staff and the people with intellectual disabilities in both sample groups. The nature of the interviews used with each of these groups is discussed in detail here.

A. Staff Interviews

Rationale

According to Schatzman and Strauss (1973), one of the primary strengths of interviewing is "revealing people's constructs of themselves and their worlds as symbolically developed and rendered: people tell what they do and why they do it" (p. 6). The series of semi-structured interviews with staff in both samples were

designed to achieve precisely this goal: to find out how staff describe what they do and why they do it.

Design and application

The interviews with staff were largely concerned with the following areas:

a. Their own attitudes about the meaning and importance of community integration, and how this related to the nature and benefit of having a variety of relationships, most importantly friendships. These issues were explored with staff in terms of their own life experience, and then in terms of how they felt about these issues for people with learning difficulties, in particular those they were currently supporting.

b. The mapping and evaluation of relationship networks for the people with intellectual disabilities whom they supported. These networks were reviewed at each interview stage, allowing for the identification of changes over time, and the exploration of the quality and character of these relationship networks.

c. Initiatives or strategies they had utilised in order to effect change in any of the individuals' networks of relationships, consideration of the attitudes they held that influenced their choice to pursue this work and the outcomes that resulted from these efforts.

d. Obstacles they had encountered in trying to assist the individuals they support to achieve community integration*, how they dealt with these obstacles and what effect this had on their attitudes about community integration* being achievable for the intellectually disabled people they supported.

e. Their attitudes and feelings about the quality of the service for tenants, and to what extent, the amount, type and quality of support for staff provided by the sponsoring organisation effected the quality of the service they provided: in particular their ability to assist the individuals they supported to develop a relationship network which offered adequate levels of community integration.*

f. Discussion, including anecdotal narratives, of the attitudes and actions of local community members and those who belonged to particular individuals' relationship networks toward the people with intellectual disabilities involved in this study. This included exploration of how awareness of this effected staff's conceptualisation of their role in maintaining or developing the relationship networks of the people they support.

[*As defined in Chapter Four]

Included in the initial staff interview for all samples was the opportunity to consider the instrumental value of various relationships in both the networks of staff and the people with intellectual disabilities whom they supported. A list of scenarios was created, which included a range of scenarios where one might require assistance from someone else. {See Appendix, p. 440} This list was designed to determine which prototype relationships people were likely to rely on in specific situations where they required assistance of some kind. The list of scenarios was completed for staff and for the particular intellectually disabled individuals being discussed in the course of each interview. This provided a basis for comparing the instrumental value of the relationship networks of staff and the people with intellectual disabilities they supported [a comparison Emerson & Hatton (1994) would welcome], while also enabling one to draw conclusions about the balance of dependence across a particular individual's relationship network.

In the primary sample, a series of five interviews was used over the 27 month post-move period with which this study was concerned. {See Appendix, p. 455 for examples of two of the interview questionnaires used.} In the secondary samples, a series of two interviews adapted directly from the content of the interviews developed for the primary sample, were used. All of these semi-structured interview schedules were first piloted with staff working in similar residential projects. Each staff interview was tape-recorded, with the permission of the staff member before and their agreement to sign the 'consent to release the interview tape' at the end of each interview. Some staff were initially put off by the tape recorder but all seemed to relax soon after the interview got underway.

Advantages of approach

In all of the interviews, the staff were found to be very open and honest, despite the sometimes controversial nature of the discussions. In some ways, this was understandable in the primary sample, since this researcher was personally known to all of the staff. However, they could have equally be more cautious with me, as I was still employed by the organisation in the first 18 months of the fieldwork phase. It seems their openness was the direct result of their personal trust in the researcher, and in retrospect, this certainly enhanced the data collected. In the secondary sample interviews, although most all staff were open and honest, some were clearly suspicious of the research subject. Their reluctance seemed to stem, at least in part, from personal cynicism about both the intellectually disabled people they worked with and the wider community. Still, the range of perspectives which the interviews generated were extremely valuable and appeared to represent a realistic spectrum of opinion.

Cautions and considerations

Like the relationship networks approach, criticism could arise over the decision to rely largely on staff perceptions of the social circumstances of the intellectually disabled people they support but the justification for this has been explained previously. However, unlike Evans and Murcott (1990) whose study relied solely on staff interviews (but appeared less able to justify this strategically since they were not concerned specifically with studying the perceptions of staff), this study also utilised interviews with the intellectually disabled individuals involved in the study.

B. Individual Interviews

Rationale

While the opinions of people with intellectual disabilities are increasingly valued by planners and providers of services (Siegelman, *et al.* 1981), there has been a long history of both policy makers and researchers questioning whether the perceptions offered by any social service clients are in fact reliable (Wallace & Rees, 1984). However, more current research seems to be addressing both the need to consider user views and the need to make the collection of those views both meaningful and valid.

In much of the past research looking at relationship issues for people with intellectual disabilities, interviews with the people themselves have figured prominently in the data collection tools.[1] However, interviewing people with intellectual disabilities raises particular practical issues which have not been particularly well addressed thus far by the research community (Atkinson, 1988a).

Design and application

Like the approach used by Richardson & Ritchie (1989), the interviews were designed to be informal and interactive, allowing the interviewees to introduce whatever language, signs, or props which would enable them to convey their message to the researcher. In some cases, people used photographs to explain their relationship networks. In other cases, they chose to identify and discuss the particular people who were important to them.

However, the interviews developed for use with the intellectually disabled people involved in this study were semi-structured. The semi-structured schedule was designed in a way that mixed open-ended and closed questions, and allowed for a conversational style which was comfortable, but largely guided by the researcher. The subject themes and specific questions which made up the interview schedule were designed to explore issues similar to those explored with staff. To maximise comparability with staff responses, the list of scenarios used with staff was also used in the individual interviews. Therefore, where staff may have been explaining their perceptions of how the intellectually disabled individuals felt about certain relationships, or who they *thought* a particular individual would choose to turn to for support, these interviews were designed to establish whether staff were making accurate interpretations of the views of those they support.

Interviews were conducted with each of the intellectually disabled individuals involved in the study and willing to participate. All three individuals from the primary sample participated, while five of the eight individuals from the secondary samples agreed to be interviewed. In the primary sample, four individual interviews were conducted with each of the tenants over the 27 month post-move data collection period. In the secondary samples, because of time constraints, one interview was conducted with each of the individuals involved in this study in the period between the first and second staff interviews. The interview schedule used in the secondary samples was, like those used with staff, adapted from the four interview schedules used with the primary sample.

A tape recorder was used, as well as notes taken by the researcher. Notes were taken in full view of the interviewee. They watched carefully as the notes were written, and understood (through this process) that the researcher was making a

record of what they were saying. Unlike the staff interviews, the researcher and interviewee often sat alongside each other, rather than facing each other. The approach this researcher took was to establish a partnership in conducting the interviews, and stress the fact that the researcher was there to learn from the interviewee.

Advantages of approach

Overall, the design and approach worked well with the majority of interview participants, and worked particularly well with the three individuals from the primary sample. The partnership approach to interviewing seemed to engender both commitment and honesty on the part of the interviewees. Interestingly, the tape recorder did not seem to "put off" any of the interviewees with intellectual disabilities in the same way it did with the staff being interviewed.

The use of semi-structured interviews ensured that a pre-determined set of subjects was discussed in a somewhat consistent way; but this approach did not preclude the recording of other comments that the interviewee made that may not have been related to the questions at hand. Where the semi-structured interview schedule did not work for two individuals from the secondary samples, this was due to the extent of comprehension and expression difficulties experienced by these individuals. In other situations where people's understanding of the questions posed proved difficult, the questions were adapted by the interviewer in an attempt to simplify their content and allow the interviewee to give an answer of some value in the interview process. This was usually successful.

Cautions and considerations

Where people who were interviewed struggled with expression, this was a challenge for the researcher. Various probes were used to establish an accurate understanding of what the interviewee was saying. This often involved the researcher repeating what the interviewee had said to ensure this was understood correctly. Interestingly, and somewhat unexpectedly, many of those interviewed were quick to tell the researcher that she had not understood their answers. However, frustration did play a part in a few interviews, and some lines of questioning had to be abandoned either because the interviewees could not understand the nature of the questions being asked, or the answers given were not discernible. It would have been possible to invite someone who knew each person well to support them in the interview, but this, it was felt, would defeat the purpose, as an honest discussion of people's relationship networks could hardly take place if a member of that network were present and involved. Yet communication problems, in particular where they significantly effected the success of the interview, were more the exception than the rule among those who were ultimately interviewed.

3. Personal Diaries

Rationale

Diaries are a data collection methodology which has only been recently recognised as particularly useful for social scientists (Duck, 1991). However, diaries have become increasingly popular in social work research. According to Seed (1990), "a large majority of clients easily become committed to keeping diaries, usually

conscientiously and sometimes enthusiastically" (p. 48). Diaries are a particularly valuable form of data if one is attempting to establish a lifestyle pattern for a subject, and where observation is not possible or is not used in such a way that it would yield such information. In this research study, the need to gain a sense of the lifestyle routine for the intellectually disabled people involved prompted the use of personal diaries.

Design and application

Diaries are of two types. More typical diaries include those which offer blank pages and ask the diary keeper to record whatever thoughts he/she wishes to record about day to day life and happenings. A second form of diary is a more structured diary which involves the keeper filling out a proforma or recording only specific information or feelings that have been requested. This study utilised a more structured diary, designed specifically to explore the daily lifestyle of each intellectually disabled individual, and their contact with others in their relationship network. The diary page used is an enhanced version of a structured diary page used by Seed (1990). {See Appendix, p. 443 for example of diary page used in this study.}

Seed describes his diary proforma as evolving "to enable clients to record the people, places and activities which are significant to them:" essential information in relationship network analysis. Enhancement of this diary proforma involved the addition of specific questions about contact with others, either by phone or post, which was judged to be an equally important indicator of relationships. Because the diary page was enhanced in a very minor way, and no significant alteration to the

original design was undertaken, it was felt that piloting of the diary page was not necessary, given Seed's successful work with it.

Seed suggests that diaries of a fortnight in length are usually sufficient for adult clients. However, he also suggests that where a particular client's life might move very slowly, a diary of a four week period may be considered. Although people with intellectual disabilities are not pre-disposed in some way to having lives that "move slowly," they are often shown to have particularly uneventful lives which are limited for a variety of reasons.[2] Given this, the number of activities or encounters that may occur in a week for an average person, may not accumulate for a much longer time in the case of an individual with intellectual disabilities. Therefore, in this study's primary sample, the diaries lasted for a period of six weeks in order to allow adequate time for a lifestyle pattern and a full range of contacts to emerge. The diaries were administered at four points over the four year period of data collection. In the secondary samples, diaries were administered at one point, between the two staff interviews, and were of a four-week duration.

Advantages of approach

The diaries collected in the primary sample covered various times of the year, including summer and winter as well as holiday seasons. The contrasting data this presented proved very useful in generating vivid pictures of the intellectually disabled people's lifestyles. As well, the diaries as a whole allowed for the generation of a longitudinal pattern of lifestyle, which spanned nearly four years. This proved useful in demonstrating both the nature of growth and change which occurred in people's lifestyles, as well as how these changes related to a pattern of contact with those belonging to people's relationship networks.

Cautions and considerations

It is important to note here that staff had a significant role to play in the completion of the diaries, either recording what was dictated to them by the intellectually disabled individuals or prompting these people about where they had been, whom they had gone with or met there, and what they had done. None of the intellectually disabled people who participated in the study were able to fill out the diaries without considerable assistance from staff. Though some might argue that this would invalidate the diary data, staff were given guidance to prompt using the questions the diaries posed, but not to record any information which each individual did not say spontaneously. In particular, staff were asked not to record names of people with whom the intellectually disabled person had spent time when staff were not also present, unless this information was surrendered by the individual in question. For example, staff were not to record all of the names of people they knew who rode on the ATC bus with the person completing the diary. They were only to record those names that this person mentioned. Staff were permitted however, to prompt individuals about particular people they had spent time with, if the staff member was also present. For example, a staff member could say "remember we had lunch with Jane", but they were asked not to suggest names of people the individual in question *might* have seen in other places like the day centre or the club. Therefore, rather than having the diaries produce large lists of people simply because they were in the same place or activity with those completing the diaries, what would be recorded was only those people whom each individual felt were significant to them. In looking at the completed diaries, it was therefore possible to know where staff may have prompted (e.g.. in situations where they were also present) and where answers, if given, were spontaneously offered by the individual in question.

4. Staff Meeting Observation

Rationale

As stated in Chapter Three and Four, there is little evidence of staff being the focus of a study which is concerned with the relationship networks for people with intellectual disabilities. This is a likely reason why there is little evidence of observation of residential support staff meetings having been used in previous studies. Most times, interviews with individual members of a staff team have been judged to be an adequate source of data. In this study, a number of factors led to the decision to utilise direct, unobtrusive observation of staff team meetings.

First, the idea that this data had rarely been collected intrigued this researcher as to the value of such data, especially in relation to studies of staff and their impact on those they support. Second, the focus on staff in this study made it important to collect as many sources of data on staff as possible. After the individual interview, the staff team meetings are an obvious second choice for collecting data on the attitudes and actions of staff. But in making this choice, consideration had to be given to whether this would produce any data that would be different from that collected in the staff interviews. If this did not result, the decision to observe could hardly be justified.

The assumption that this observation would indeed produce different data, and was therefore worth doing, evolved for two reasons. First, the interviews were concerned largely with a specific and limited part of staff's work: namely, their work in relation to the relationship networks of the tenants. Observing the staff meetings, on the other hand, would give an overall picture of the staff's role,

illuminating the priorities and range of agenda items that staff had to deal with at any one time. This would provide further insight into where work on relationship networks fitted into the overall role of staff. Second, it was assumed that the attitudes and opinions of staff (as individuals) might be different than those they would express as part of the group (the staff team). This assumption evolved from studying Derek Newman's theory on organisational analysis.

Newman (1968) identifies four aspects of the organisation when analysing its effectiveness:

1. The Manifest Statement: the organisation's objectives and mission as it is formally described, codified, or displayed;

2. The Assumed View: the organisation's objectives and mission as it is variously assumed to be by individual members of staff;

3. The Extant View: the organisations objectives and mission as revealed by systematic exploration and analysis;

4. The Requisite Conclusions: the extent to which the "extant" (or observed reality) matches up with the "manifest" (the professed objectives and mission).

(Newman, 1968, p. 9)

According to Newman, to the extent the extant and manifest match, the organisation is effective.

Interestingly, it was not only the relationship between the manifest and the extant that intrigued me, but also the idea that there is an assumed view among individual members of the organisation's staff. What struck me in addition, was the possibility that there may also be an assumed view of a group of staff, especially in large organisations where sub-cultures are likely to exist among the various staff sub-teams. Given the logic of this possibility, it seemed likely that considering the

views of individual members of staff might generate different data from that which was designed to ascertain the views of the staff team as a whole. Although within the team, individual staff are still expressing individual opinions and attitudes, they are doing so within the social context of the group, and this may alter their responses. In an article by Smiley (1982) entitled *The Abilene Paradox*, he describes how people within a group or organisation will act in contradiction to their personal understanding of the problem at hand, because they feel anxiety about acting in this way, or because they may experience strong pressures against deviation from the group's agreed position. Smiley says:

> There is a fear of the right action. The people know what to do. They can't bring themselves to do it...The core of the Abilene Paradox lies in the individual's fear of the unknown. Separation, alienation, and loneliness are events we know and fear. Ostracism is one of the most powerful punishments known to man...The fear of taking risks that may result in our separation from others is the core of the Abilene Paradox. It is the cause of the self-defeating, collective deception that leads to self destructive decisions within agencies and organisations. (p. 55, 56-7)

In this example, group harmony and the retention of positive membership within that group set the stage for individuals to compromise what they think and do. Cartwright and Zander (1968), in discussing the pressures to uniformity in groups, point out that there may be still more reasons why conformity - this time naturally occurring - often prevails. The authors notes that there exists a peculiar homogeneity in established group members' environments and "because of the relatively restricted range of events encountered by the members of the group, they come to know, perceive, and do things in a similar fashion" (p. 140).

These commentaries on the power of a group to shape and reinforce individual attitudes can clearly be taken to suggest that there may be critical differences between a staff member's attitudes expressed in a one-on-one interview and those

expressed within the wider team. Since decision-making for action is typically taken at the team level in residential services, the difference between what the staff member says on a one-on-one basis and what the staff member says in the group needs to be understood, and the implications of these differences recognised within this. On this subject, Cartwright and Zander note that the pressure to conform often results from "approved procedures for movement toward an agreed upon goal" (p. 142).

For these reasons then, the decision was taken to study, through observation, the formal meetings of the staff teams involved in this research. The focus of this research makes it important to understand the pattern of staff attitudes and actions within a broader organisational context. There is a need to understand at what level, different decisions are made. It was envisaged that the data collected would help illuminate the patterns of decision-making that a particular staff group went through in determining what they would do to assist tenants in their daily lives. As well as things specific to relationship network development, this observation would also make it possible to assess the priorities of staff at any given time, and the role that the sponsoring organisation's management had in shaping these priorities. Finally, the data collected would enable this researcher to evaluate how the team priorities matched up to the formal mission and objectives of the organisation in a spin-off of Newman's organisational analysis approach.

Design and Application

Unobtrusive observation is probably the simplest form of observation a researcher can undertake. Done with consent, it does not carry the ethical implications of covert observation; yet it does not distract the concentration of the researcher in

collecting the data, nor make the researcher's presence have as significant an impact on the situation as participant observation would. Unobtrusive observation can involve the collection of many different types of data. The researcher may be filling in quantitative schedules, writing notes on the course of events being observed, or taking notes on the content of the conversations being observed. In this case, because of the need to explore the actions and attitudes of staff, particular attention was paid to the content of the conversation in the staff meetings observed. To avoid missing or failing to record conversational data which then evolved into something relevant to the research, a saturation approach was used in taking notes during observation. Times were recorded throughout so to a limited extent, the balance of time staff spent on various issues could be gauged. As well, speaker identifiers were used with the primary sample, and as far as possible in the secondary samples.

Observation of staff meetings occurred primarily around the time that a set of staff interviews was taking place. This was intended to give the interviewer a sense of the issues which were around for the staff team at a particular time. In the primary sample, a total of eighteen staff meetings were observed. In each of the secondary cases, four staff meetings were observed (a total of sixteen).

Advantages of approach

The observation notes produced read more like a transcribed group interview; but provide extremely useful evidence of the course of events and conversation in each staff meeting observed. This proved particularly valuable in identifying expressed attitudes and accounts of actions for analysis, as well as in exploring examples of dissension within the group and any pattern of mediation which served to reconcile this. Observing around the period in which individual staff interviewing was taking

place made the content of the staff meetings and interviews directly comparable in terms of specific themes, issues, or events. The existence of directly comparable data made it easier, in the analysis phase, to determine if in fact there were significant differences between the attitudes expressed by individual staff members and those expressed in the team context. The use of speaker identifiers enhanced this. Also, conducting the observation at these times provided me with a basic knowledge which facilitated the individual interviews with staff (my understanding of the stories or issues they were discussing).

Cautions and considerations

Use of a tape recorder was not thought to be feasible as there were concerns about acoustics. Also, each staff team trusted the researcher to record information relevant to the research but to respect the confidentiality of other issues that were raised in the course of their meetings. It was felt that tape recording would have engendered a greater anxiety in the staff team, as all of the dialogue would be recorded.

5. The Likert Scale

Rationale

The measurement of attitude is a complicated process. According to Zimbardo and Ebbesen (1969), the major problem with attitude research is "the lack of common methods for measuring attitudes, and a similar confusion regarding the definition of attitudes" (p. 61). What evolves from using different methods and measures is the

potential for the exact same attitude response to be viewed quite differently across studies using a range of methods and measures. Beyond these basic problems in measuring attitude, the choice of quantitative or qualitative method of attitude measurement is somewhat dubious. Quantitative approaches to measuring attitudes can provide clear measures, which yield cogent data that can generate convincing conclusions. Yet qualitative methods which explore attitude have a different, not lesser, value than quantitative methods. Qualitative methods involve an experiential focus, where the researcher becomes better able to understand the nature of the attitudes she is measuring, therefore reaching more prudent conclusions with regard to the nature of specific attributes of certain attitudes. Like Wellman (1977), who used open-ended interviewing to explore the nature of racist attitudes, my use of interviews and observation in this study afforded an opportunity to study the particular attitudes expressed by staff in a deeper sense than a quantitative approach. However, in order to benefit from the strengths of a quantitative approach, I chose to complement these qualitative methods with a Likert scale: perhaps the most popular quantitative tool for measuring attitudes.

Design and application

The Likert scale was developed with the intention of generating, from multiple respondents, more directly comparable and quantifiable data than would be generated by the interviews and observation. The use of Likert scales is a common choice for measuring attitudes among social service workers. In a study exploring the relationship between work satisfaction of nurses and the quality of care in psycho-geriatric wards (Gilloran, *et al.* 1993), Likert scales were used to measure work satisfaction and morale among the nurses involved in the study. Further, in a

study by Barr (1990), a Likert scale was used to measure the attitudes of nursing students toward people with intellectual disabilities.

The Likert scale devised for this study {See Appendix, p. 444} includes a number of themes common to working with people with intellectual disabilities. Special emphasis was placed on incorporating statements addressing relationship issues and the management of the agency employing staff. Within the scale, there are a balanced number of negative and positive statements about each of these subjects. Staff have been asked to rate their agreement with each statement on the common five point scale.

Staff in the primary sample completed the Likert scale prior to the move and again at a point 25 months after the move. Booth (*et al.* 1990) points out the importance of collecting baseline data to facilitate the study of change in a longitudinal study. The Likert scale offered a way to collect some baseline data on staff attitudes, given that there was insufficient time to interview staff prior to the scheduled move. The scale was re-administered to assess changes in the staff's attitudes after the move had taken place and a significant period of time had passed. Staff in the secondary samples, including those interviewed and the remainder of the staff teams of which they were apart, completed the Likert scale once during the fieldwork period in which they were involved. No pre-move scale was possible, since all of these sample groups had been located in the community for some time before data collection began.

Advantages of approach

In both the primary and the secondary samples, the Likert scale made it possible to consider the relationship between staff attitudes toward agency management and their attitudes toward people with learning difficulties. In the primary sample, the Likert scale enabled a longitudinal assessment of attitude change among staff on key issues important to the research focus. In addition, because the scale was administered twice, it became possible to explore whether changes in attitudes toward agency management were related to changes in attitudes toward people with intellectual disabilities. Ultimately, comparisons of the cumulative responses from all staff who completed the Likert scale, both in the primary and secondary samples, offered a vital picture of the balance of direct support staff attitudes regarding relationship issues for people with intellectual disabilities.

Cautions and considerations

A drawback of the Likert scale is that it asks staff to generalise about people with learning difficulties and does not allow for differences among individuals (Barr, 1990). However, in this study it was assumed that staff would answer with those whom they support most central in their minds. Therefore, the attitudes revealed in the Likert scale were thought to be strongly linked to staff's attitudes toward the specific people they support.

6. Agency Documents

Rationale

Documents are a key data collection method in case study research. In terms of data triangulation, they provide an important perspective on the case, especially when that case is occurring within an organisational context. As explained previously, agency documents provide what Newman terms the "manifest statement" for these organisations. To assess an organisation's effectiveness, the content of these documents is compared to the reality of what is being observed and understood by studying the organisation in action.

Also, analysing agency documents can further one's understanding of how an organisation works, and how this affects the staff's ability to achieve the organisational objectives which have been set. Newman (1973) suggests that the formal structure of an organisation could inhibit the achievement of the organisational objectives, especially where new objective are approved by individuals in the organisation, but the organisational structure does not change accordingly.

> On the other hand, in one situation known to me a sharp conflict has built up between the informal structure, which, reinforced by environmental factors, has developed in line with new objectives because they are approved of by people in the organisation, and the formal structure which has not changed. This is a very sad state of affairs, where the formal structure, which should enable and encourage the carrying out of relevant activities is in fact inhibiting them... (p. 72)

Newman goes on to state that new organisations, which begin with innovative objectives, can often become traditional in form and thus function in conflict with

these objectives. Often it seems, the pressures to become traditional evolve from the way in which other, similar organisations have been structured.

> On occasion, this sort of situation arises when a new organisation is set up...Because it is considered to be in a particular field, say...social service, it is organised in the way of that field in general, or as organisations in that field are supposed to be. This can result in a discontinuity ab initio between the implications of the objectives and the organisation structure; the structure often rapidly develops a stability and coherence of its own which is then very difficult to change. (p. 72)

Overall, I concluded that the extent to which organisational objectives relate to the structure within which the staff operate, and more importantly to the role and purpose of staff, could be most efficiently explored through access to agency documents. Therefore, such documents were thought to be a necessary part of the data collected and considered in this study.

Design and application

In this study, these documents were requested through middle or upper level managers and were provided by all of the organisations involved. Agency documents which related to the following areas were collected:

> *Aims and Objectives of the organisation.
>
> *Organisational statements or policies on relationships which would directly influence staff's role. For instance, policies on sexual relationships, family relationships, relationships between staff and those being supported, etc.
>
> *Job descriptions for the line staff involved in the research.
>
> *Statements or policies on volunteers, citizen advocates, befrienders or other similar relationships.
>
> *Statements or policies in relation to risk-taking, particularly in the area of relationships.

Advantages of approach

In the analysis of these documents (discussed in the final section of this chapter), I looked particularly at how the agency documents addressed the importance and value of relationship networks and community integration for service-users. Additionally, I explored how each of these documents carved out a role for staff in this developmental area. I then compared this to the evidence both of staff's perceptions about their own and the agency's stance on these issues, and the more practical evidence of staff in action. Through this I was able to determine the extent to which the content of agency documents shaped the attitudes and activities of staff.

Cautions and considerations

One drawback, in research terms, is that the organisations involved in this study were often changing, re-writing, or updating such documents. This usually seemed to take the form of applying greater specificity to what were originally open statements of intent. In the first sample in particular, where a longitudinal process of data collection was undertaken, some of these agency documents changed. Consequently, both old and new needed to be considered within the process of analysis.

The interplay of the data collection tools

Having introduced the six data collection tools used in this study, it is important to understand the way in which these tools interfaced to generate a comprehensive set of data on the subject being studied. Within the secondary samples, there were only logistical changes in the data collection plan (as opposed to more fundamental changes in the tools being used) which resulted from the need to locate new projects to act as the secondary samples. Rather than pursuing a full replication of the pattern of data collection used with the primary sample, as it was hoped would be possible originally, the secondary samples involved a more limited process of data collection, which was nonetheless derived from that used with the primary sample.

Improving validity through triangulation of the sources of evidence

In its favour, a major strength of a longitudinal design and small sample is the opportunity to collect many different sources of evidence. The use of multiple sources of evidence to maximise triangulation of data for analysis is a readily accepted strategy for improving construct validity (Yin, 1994). Collecting and analysing multiple sources of evidence allows the researcher to consider a number of perspectives relating to the same phenomenon. Thus one key purpose of data collection is based upon the need to obtain converging data from a variety of sources. This particular form of triangulation, where validity is achieved through the convergence of multiple data sources, is what Denzin (1978) refers to as "data triangulation." In this approach, researchers use as many different data sources as possible to examine events under analysis. Another type of triangulation which has been particularly relevant to this study is what Denzin refers to as "methodological triangulation." This form of triangulation emphasises utilising different forms of

data collection methods to study the same phenomenon. In this study, the primary criteria for establishing validity has been achieved through the interplay of the six data collection methods used, allowing for both data and methodological triangulation.

An outline of the multiple sources of evidence available

1. *Data required to address the research question:*

   *The nature of the lifestyles of the people with intellectual disabilities involved in this study.

   Methods utilised to study this phenomenon:

   1. Diaries
   2. Staff Interviews
   3. Staff Meeting Observation

2. *Data required:*

   *The nature of the relationship networks of the people with intellectual disabilities involved in this study, including changes over time in these networks.

   Methods utilised:

   1. Staff Interviews
   2. Diaries
   3. Tenant Interviews
   4. Staff Meeting Observation
   5. Mapping Relationship Networks

3. *Data required:*

   *The role of staff and how it is conceptualised by the individual staff and sponsoring organisations involved in this research.

   Methods utilised:

   1. Staff Interviews
   2. Agency Document Collection
   3. Staff Meeting Observation
   4. Likert Scale

4. *Data required:*

*The attitudes of staff, in particular the attitudes they hold in relation to people with learning difficulties and their relationship networks.

Methods utilised:

1. Likert Scales
2. Staff Interviews
3. Staff Meeting Observation

5. *Data required:*

*The activities and actions of staff, both as a group and as individuals.

Methods utilised:

1. Staff Meeting Observation
2. Staff Interviews
3. Diaries

6. *Data required:*

*The aims of the sponsoring organisation, particularly in relation to community integration, and how these aims are operationalised.

Methods utilised:

1. Agency Document Collection
2. Staff Interviews
3. Staff Meeting Observation

How the various data collection methods complemented each other

The six data collection methods complemented each other in a number of ways, and collectively as well as individually contribute to the validity of the study. In the case of observation, Stake (1994) notes that observations which are pertinent to the issues being studied, work the researcher toward a greater understanding of the case (p. 60). Stake also notes that document review can provide key repositories of information or measures for the sample, or they can serve as substitutes for records

of activity that the researcher could not observe directly (p. 68). In this study, documents served both purposes: agency documents provided information on organisational intentions which could then be compared with actual practice and outcomes; while the personal diaries offered a snapshot of each intellectually disabled person's lifestyle which could not have been practically observed.

In addition, interviews allow researchers to obtain the descriptions and interpretations of others which enable them to learn about what they cannot observe for themselves (Stake, 1994). Interviews in this study enabled what Booth calls "complementary points of view" to be obtained (*et al.* 1990). Since it is generally accepted in interpretive research, that a particular subject under study will not be understood and observed in the same way by everyone, the multiple points of view offered by those being interviewed in this study were particularly valuable. Although different from investigator triangulation, the views of both staff and tenants assisted this lone researcher to clarify and explain the nature of the subject more accurately. Finally, in the pursuit of the balance which Corner (1991) and others argue for, the array of data collection tools used in this study offered scope for both qualitative and quantitative analysis. This brings me to the question of the approach to data analysis used in this study.

Part 4: Data Analysis Methodology

Considering how to address the main objectives of the study

As stated earlier, in an effort to move beyond the scope of previous research, the chapters which follow (and present the findings of this study) are intended not only to document *what* was occurring in relation to community integration outcomes for the intellectually disabled people studied, but more importantly, to begin to offer a provisional yet empirically-based explanation as to *why* these outcomes resulted. Furthermore, the approach to data analysis was designed specifically to allow consideration of how and to what extent direct support staff contribute to the outcomes.

Clearly, adopting this focus involved beginning with an assumption about cause and effect: I assumed, based on my review of the existing literature, that support staff were *likely* to have a significant role in determining the community integration outcomes that evolved for the intellectually disabled people whom they supported. Miles and Huberman (1994) warn that "*assumptions* have a driving, controlling quality" over the explanations one gives for observed outcomes. Yet they argue that when a researcher makes explicit her initial assumptions, so that the connections between theory and conclusions are clear, she enables the study to be assessed by the strength of the explanations given (p. 143). According to Hanson (1958), the quality of the explanation is what ultimately succeeds or fails at connecting causes with observed events.

While some may argue that sound methodology requires one to consider rival hypotheses, I took the view that isolating a series of single variables becomes

virtually impossible when considering things, not in a laboratory, but in their natural context (Abbott, 1992). Given this, I chose to address the significance of the role of direct support staff in detail, rather than as one of many potential causes. Consequently, this study was by no means a traditional variable-oriented 'cause and effect' study, in part because it was possible neither to isolate the variable of staff nor to undertake an experiment involving a control group.[3] Instead, my approach offered an avenue to developing explanation about something which exists in a particularly complex context. Ultimately, whether explanatory theories are developed from the laboratory or the field, Kaplan (1964) makes the important point that explanations of any kind are "always open: they depend on certain conditions and are partial, approximate...and typically limited to specific contexts" (pp. 351-355). *In accepting this, what this study* ***will*** *demonstrate is how strongly and in what ways the evidence suggests that staff were a significant factor in the relationship network and community integration outcomes of those they supported.*

In order to address these intentions within the context of generating explanatory theory, the process of data analysis introduced in the next section led to the development of a provisional explanatory framework, which offers a basis for considering analytic generalisation. Given the framework's potential in this regard, the secondary samples were used to *test* the provisional explanatory framework , in order to determine the generalisability of the framework and to elaborate my initial understanding of it. With this in mind, the steps followed to undertake the data analysis and draw conclusions from this process, which were then used to develop the framework, are described next. Where the framework is ultimately introduced in Chapter Eight, I have explained the thought processes that I went through to move from the conclusions, which resulted from my analysis of the data, to the development of the explanatory framework.

Developing a frame of reference for the analysis phase

My approach to data analysis took cognisance of a number of comments, made in the literature, about the analysis of qualitative material. First, in adopting the perspective of a grounded theorist, I undertook the primary analysis phase just prior to writing up the findings; yet this subsumed many earlier pieces of analysis which were carried out at each stage of the fieldwork process. This approach to data analysis is consistent with a grounded theory perspective, where there is typically a continuous interplay between the data and the evolving theory. My approach also mirrored that of longitudinal analysis, which according to Holmes and Poole (1991) involves a considerable commitment of time and effort which is repaid by "a familiarity with the subject that fosters deep understanding and novel insights" (p. 286).

In addition to adopting this *pattern* of analysis, within it I operated largely from an interpretive perspective, seeking to make sense of my data by thinking about it as deeply as I could (Stake, 1995). I adopted Stake's method of analysing qualitative data quantitatively (through what Stake calls the *categorical aggregation* of a number of related instances) where one seeks to consider "the emergence of meaning from the repetition of phenomena" (p. 76). While there is no one, ideal approach but rather a collection of approaches that can effectively render explanatory theory, I chose Stake's approach because it was particularly suited to dealing with the variety and types of data I had collected. Likewise, I recognised that the ultimate strength of the analysis lies not only in choosing a solid approach, but more so in how well it has been applied.

Given the enormous amount of data I had collected and the time-limited period I had available to me for analysis, I resisted attempting to consider particular types of

the data (e.g. interview transcripts) from a variety of analytic perspectives. I was concerned that such an approach might have caused me to 'drown' in the process of analysis rather than 'immerse' myself while retaining an ability to withdraw, reflect and move on to developing conclusions. Meanwhile, I took account of the vital importance of the *chain of evidence*, typically considered proof of the legitimacy of case study findings, but also highly relevant to my study, given the complexity of the data collected and the intent to develop explanatory theory. By attending to the *chain of evidence*, Yin (1994) explains that those considering the findings of a study should be able to see how the researcher arrived at her conclusions, and how these conclusions can be traced backwards to the evidence that supports them and then to the research questions that guided the collection of that evidence (p. 98). Within this, he stresses that no evidence should be lost or ignored. While agreeing that this should not happen out of ineptitude or carelessness, I also concurred with Stake's assumption that "almost certainly, there will be many more data collected than can be analysed, and it is important to identify the best and set the rest aside" (1995, p. 84).

Therefore I began the analysis phase by undertaking an initial period which involved thorough sorting of the data. This enabled me both to systematically identify those sections of the data which were most relevant to addressing the various research questions that I had set, and to then assemble this data in ways that would facilitate analysis. These steps and an overview of the main approaches to analysis which were used are explained next.

The general analytic strategy

Yin (1994) advises that "every investigation should start with a general analytic strategy - yielding priorities of what to analyse and why" (p. 102). The analytic strategy I adopted began with returning to the four broad areas of investigation which underpinned the research questions in this study.

1. Evidence of support for community integration and the definition used in this study.

2. Evidence of a recognition that the levels of community integration achieved are less than satisfactory and that there is a need for greater levels of community integration.

3. Evidence of initiatives undertaken to promote greater levels of community integration.

4. Evidence of the effectiveness of staff initiatives to promote greater levels of community integration.

As mentioned above, I then went on to identify the data I had available to me which in some way addressed each of these areas and the research questions related to them. Sorting the data in this way involved a process of selection which Bakeman (1991) states "provides the foundation on which all subsequent analysis rests" (p. 256). This sorting was a necessary first step in this study particularly, since a single raw data set (e.g.. an interview transcript) often addressed a number of research questions.

From here, the analysis of the data related to each of the four areas identified above began to reflect the types of data with which I was working.

Making sense of different sources of data: the first-level analysis approaches

1. Personal Diaries and Relationship Networks

The diaries and relationship networks were used primarily to inform the development of portraits of the intellectually disabled people involved in this study. The portraits document their community integration outcomes and the quality of their lifestyles and relationship networks. In analysing the diaries and networks, I was interested particularly in discovering what part people's various relationships played in their daily lives, and the extent to which any changes in people's lifestyle appeared to correspond with changes in their relationship networks or vice-versa.

The diaries and networks were initially assembled in chronological order, a basic approach recommended by Miles and Huberman (1994), to allow for analysis which could uncover evolving patterns in the intellectually disabled people's lifestyles and relationships. I first considered the group of relationship networks collected for each individual, quantifying the following information:

a) the balance of membership across the five categories of relationships considered in the network;

b) the changes in an individual's network which evolved over time, including additions, promotions, demotions and losses;

c) the extent and way in which people with and without intellectual disabilities figured in each person's network, and how this changed over time.

I then undertook a review of each diary, recording tabulations on the following issues:

a) the variety of places an individual spent time;

b) the pattern and frequency of contact an individual had with various people in his/her network; and

c) the number of times various people in an individual's network were mentioned in each diary.

The relationship networks and diaries for a specific individual were then cross-referenced, generating what Seed (1990) calls an analysis of *the social landscape* of people's lives: an understanding of the people, places and activities that are important to an individual in daily living. By cross-referencing this information, issues related to network features and relationship qualities could be analysed. Things like the amount of time spent in integrated versus segregated settings; the amount of time spent within or without the home; the amount of time spent with the various people who belonged to the relationship network; and the balance of time spent with people who have intellectual disabilities and people who do not, are just some of the important areas which were considered.

The results of this process of analysis, along with the information collected and analysed from interview and observation transcripts, formed the basis for writing the portraits which are presented in Chapter Seven. Finally, the diaries and networks were also used to cross-check both the validity of staff's opinions, and the accuracy of their accounts of events, which were gathered in either the interviews I conducted or the staff meetings I observed.

2. Documents

Agency documents were subjected to what Hakim (1987) calls *analytical reading*, where the content of these documents was analysed and various sections were coded

according the broad areas that the research questions demanded be considered. These areas included:

a) statements of general aims;

b) evidence of operationalisation of these aims;

c) statements about the role of staff;

d) evidence of priority-setting in any of the above areas; and

e) evidence of reference being made to community integration.

Data from a single agency, with similar codes, were then clustered and analysed. From this, I was able to draw conclusions about the agency's philosophical position and practice priorities. By then comparing these conclusions with data which addressed staff's perceptions of the agency, I was also able to determine to what extent staff's perceptions matched the documented evidence. This contributed to my understanding of how effective the agency appeared to be, from Newman's perspective which involves comparing how well the agency's manifest situation (the situation as it is formally described) matches the extant: "the situation as it is revealed by systematic exploration and analysis" (1968, p. 9).

Since all of the documents analysed were text-based rather than numerical, the content of the documents could be considered as narratives that were then easily comparable. Documents from a single agency were ranked according to their scope and significance, and lower-order documents (e.g. time-specific reports, public relations materials) were used to elaborate (but not negate) the content of higher-order documents (e.g. aims & objectives, job descriptions, business plans). Strict comparison on this basis, between the documents provided by the five different sponsoring agencies in the study, was not possible as they each provided a range of documents, some of which were consistent with those provided by other

agencies (typically, the high-order documents were consistently provided) and some of which were not.

3. The Likert Scale

The results of the Likert scale completed by members of each of the staff teams involved in this study were aggregated to yield the balance of attitudes which existed in each team. What was of particular interest was staff's attitudes about people with intellectual disabilities and the agency management. The balance of responses to each statement was represented as percentages which facilitated comparison between the results from individual staff teams. In the primary sample, where the scale was administered prior to the move and then at a point thirty-nine months later, the results at each point were compared to identify any changes in staff's attitudes which had developed in the interim. In addition, because the Likert scale was also administered to each of the secondary sample staff teams, comparisons of attitudes among staff from the various organisations were made, and this contributed to my understanding of the range of views among staff from different organisations, as well as within a single staff team.

4. Interview and Observation Transcripts

The interview transcripts and observation notes were used to address in some way every research question posed, and consequently, these transcripts represented the majority of the raw data to be analysed. Therefore, beyond the initial sorting, organising the masses of data to be considered required a number of steps. First,

similar to the approach advocated by Stake (1995), a set of pre-established categories, intended to address the research questions, were used. I broke down the complexity of each research question by developing a set of thematic categories which related to the question. Each data chunk from the sorted data was then considered and assigned, through a cut-and-paste process, to the relevant thematic category. In the case of the interviews, this was a rather straightforward process since the semi-structured nature of the questionnaires meant the data could be easily divided according to the research questions they related to. This was not however, the case with the observation transcripts which were lengthy and unstructured dialogues. For this, I had to undertake a *sequence of readings* designed to allow thematic categories to emerge, particularly related to staff's attitudes and activities, the agency's activities, and the attitudes or actions of community members.[4]

These processes created clusters of data corresponding to each category, and also allowed for new thematic sub-categories to emerge naturally in the process of reviewing the data. For example, where data from the transcripts were clustered under the categories of either staff attitudes or staff activities, within these, similar examples could be grouped and analysed, allowing for a sub-category or theme, which illustrated each sub-group particularly well, to emerge and be applied. Chapter Eight discusses the ten themes related to staff attitudes and activities that evolved from this process of analysis, and formed the basis for developing the provisional explanatory framework. Overall, this process of working with the interview and observation transcripts allowed for analysis through categorical aggregation to be undertaken, which provided the basis for developing conclusions.

Second-level analysis: generating conclusions from the variety of categorised and clustered data

Through the process of clustering the data described above, decisions were made about how the data would be both differentiated and combined for analysis. Clustering in this way achieved the necessary organisation of the data for categorical aggregation. According to Stake (1995), categorical aggregation involves:

> ...the aggregation of instances until something can be said about them as a class. (p. 74)

Although a seemingly straightforward mode of analysis, as a further check I drew on the systematic approach to qualitative data analysis advanced by Michael Agar. Agar's technique, loosely called a *'strips and schema'* approach, is a form of categorical aggregation, done systematically in order to "translate the researchers' own taken-for-granted procedures for knowledge acquisition into a tangible method that can be critically assessed" (1986, p. 7).

Michael Agar's *strips and schema* method of analysis for promoting ethnographic understanding involves a number of pieces of data being aggregated and then systematically analysed to yield conclusions that can then be systematically verified. In Agar's approach, strips are any bounded phenomenon against which a researcher can test his or her understanding. (1986, p. 28) In this study, a strip was made up of the various data chunks that had been similarly categorised and therefore grouped together for analysis. Strips form the basis for analysis, from which the researcher generates *schemas* (conclusions) through interpretation of the strip. According to Agar, schemas are the 'frames of meaning' that a researcher applies to a given strip by way of interpretation (p. 19). Each schema represents a researcher's conclusion about the meaning of a particular strip.

The strips and schemas process of analysis is concerned with achieving resolution between the data chunks within the strip and the interpretation applied to it. The process of reaching resolution occurs, not by making the data fit the schema, but by repeatedly revising the schema in light of the various data chunks which make up the strip, to develop a valid conclusion that can be drawn from the strip overall. This has great parallels with grounded theory, where the developing theory is constantly reapplied to the data to ensure it truly reflects what it is meant to explain. Agar uses the term *coherence* to describe what results from the process of resolution: when an applied schema can be adopted as an accurate interpretation of the strip of data being considered.

This approach contributes to the development of theory generation through what Agar refers to as *schema resolution*. According to Agar:

> ...schema resolution is critical (for) the development of higher-order schemas that show the relations among several lower-order ones. We can't get there with a list of schemas; instead, the list must be transformed into a pattern. (p. 31)

In this phase, the schemas are grouped together, and the researcher begins to identify patterns of connection between the schemas: a logical approach, it seems, to developing explanation. Agar explains that schema resolution can uncover both pre-requisite--outcome relationships and cause--effect relationships: two approaches essential for generating explanatory theory (p. 30). The primary strength of Agar's 'strips and schema' approach is that it provides a systematic way to draw conclusions from data that builds from the ground up and has the capacity to ultimately generate broad-based theory. Such an approach seemed particularly relevant to the tasks I'd set myself in this thesis and therefore was adopted as a guiding technique, for the process of drawing conclusions from the data and moving

on to generating explanation from this. As stated earlier, the process used to generate the provisional explanatory framework which was ultimately developed is explained where the framework is presented (in Chapter Eight) to facilitate the reader's understanding of the logic underpinning the framework.

Chapter Conclusion

Having set myself the task of both exploring and explaining, and in doing so endeavouring to collect a range of different types of data in a longitudinal way, the fieldwork period of this study involved a considerable amount of time. The logistical problems discussed in Chapter Four only added to what was already intended to be a lengthy and complex undertaking. Yet, the potential to consider generalisability, which resulted from the group of secondary samples I eventually came to identify, both strengthened the overall research study and excited this researcher about its wider potential. The various data collection methods provided a comprehensive picture of each project studied, particularly the primary sample, which strengthened my ability to ultimately generate explanation. The process of analysis, which was complex both due to the amount of data I had collected and the way in which it had to be managed in order to achieve the main objectives of the study, was in retrospect, a formidable task. The systematic thought processes of Agar were akin to those I myself had to adopt in order to manage the process of writing up the findings and conclusions of this study. Yet the results appear to be far richer than what may have evolved from a more narrow, less 'messy' study than this one. With these reflections shared, I now turn to my discussion of the findings and conclusions from this study.

[1] For example: Richardson & Ritchie (1989); Atkinson, (1988); Flynn, (1986); and Booth, (*et al.* 1990).

[2] Emerson & Hatton (1994) concluded that, compared to the general population, people with intellectual disabilities who live in community-based services can expect to "spend most of their day waiting for activities to happen or to be engaged in passive and relatively purposeless activities." (p. iii)

[3] It was not felt that people with a level of intellectual disability comparable to the primary sample could have been found receiving no support. There was a possibility of comparing different types of support (a staff team versus family or other informal carers) but this was not pursued due to the desire to focus primarily on staff: not just whether they appear to influence community integration outcomes, but an intensive look at how they do so.

[4] Undertaking a sequence of readings is an approach suggested by Mauthner and Dussett (1997).

PART THREE.

Findings and Conclusions

CHAPTER SIX

"Declared Positions & Intentions: A Baseline Look at the Agency & Staff Team"

Chapter Overview

As a first step to considering the staff team at the centre of this study, this chapter explores their views about the subject of community integration and how it figures into their work. In addition, by way of introduction to the agency which supports this staff team, this chapter considers both the philosophical underpinnings of the agency as well as evidence of its formal operational agendas. Collectively, the information presented is intended to provide a context by which the activities of the staff team and its supporting agency, and their consequent impact on the community integration outcomes of those they support, can begin to be understood. Consequently, this chapter reviews the initial views and stated positions of the staff team and agency on three critical issues which underpin this study:

1. the importance and meaning of community integration;
2. the process of developing new relationships;
3. the role of direct support staff in facilitating community integration and new relationships.

What evolves at the end of this chapter is a rich baseline of information about those whose actions in relation to community integration are of central interest to this researcher. The various positions adopted by staff and their supporting agency on

the above issues form a useful basis for establishing a set of expectations about the likely extent of community integration achieved by those being supported, and the likely priorities and activities of the staff team. These are the issues discussed in the chapters which follow.

Introduction

Those who study the meaning and use of language would no doubt agree that what people choose to say, and how they choose to say it, offers vital clues about the assumptions and beliefs that underlie these statements. Some, however, might advocate disregarding words, preferring instead to draw conclusions about people's beliefs and motivations from their actions. Yet evaluating the actions of an individual, group or organisation, and intending to do this in the thorough and systematic way that research demands, requires one to consider, in addition to actions, the declared statements or positions adopted by the study participants toward the subject being studied. Therefore, by way of embarking upon the data collection for a study looking at the concept of community integration, the first task was to determine the articulated positions of the agency and staff on this subject.

For the agency, this was determined by looking closely at the documents they produced. For staff, this was achieved by asking questions in individual interviews which provoked staff to share their attitudes, understandings, and assumptions about the issues at hand. The findings from the relevant portions of the data collected are summarised here.

A. The importance and meaning of community integration

I began by considering the critical concept which is the focus of this study. In particular, the eclecticism which surrounds the meaning of community integration, that I alluded to in the early chapters of this thesis, demanded that clarification of the agency and staff's view of this concept be established as an essential starting point. As well, since an *evolved* definition of community integration had been developed for use in this study, the extent to which the agency and staff's view of community integration was consistent with this definition also required consideration.

1. The agency's position

Sixteen documents collected from the agency were dated before or during the field work process. They collectively spanned three years, from the agency's inception to a point nine months into the post-move fieldwork period. The documents collectively presented a coherent and consistent message about the agency's position. What was most obvious on first reading was that no mention of 'community integration' appeared in any of the documents. Interestingly, where 'integration' was used in the documents, it reflected a meaning similar to that intended by a number of the policy documents critiqued in Chapter Two: the integration of services, rather than people with intellectual disabilities. For example, a business plan described the goal of establishing "a growing integrated community housing network."

Where the term 'network' was used, beyond describing the development of housing, it was also focused on the service, rather than its users. An excerpt from the agency's aims reads:

> The agency aims, through its Management Committee and its membership, to provide the opportunity for informal and statutory bodies to work together in developing a network of support across the District.

Reference to the spirit of community integration was made however, through O'Brien's *Five Accomplishments* (1987) which were quoted in the aims and philosophy statement of the agency. The accomplishment referred to as 'relationships in the community' was described as "being part of a variety of personal relationships, including those with close friends." As well, the text went on to acknowledge existing relationship shortcomings for people with intellectual disabilities, saying they "are in danger of having few relationships, most of which are with clients, staff of services, and (not always) family members, while many of these relationships will be temporary and superficial."

More direct expressions of intent were also found in this statement of aims and philosophy which articulated a commitment to "encourage and facilitate befriending arrangements and neighbourhood involvement." A revised version of this guiding statement also included a commitment to providing users with "encouragement and support to form new friendships within their local communities and to maintain established relationships." While these documents represented some positive intentions at an agency-wide level, a paper which outlined plans for the closure of the hostel where the three individuals at the centre of this study lived, demonstrated the first, focused intention on relationships as a *priority*. In this paper, the remaining four accomplishments suggested by O'Brien are described as:

> ...steps to developing good relationships with families, friends and other members of the local community. Each individual will be helped to mix with ordinary people in the course of their lives with a view to establishing a range of good relationships, including acquaintances, true friendships, and intimate relationships.

Overall however, despite these positive utterances, on balance, the collective content of the sixteen documents raised serious concerns about the *relative* importance of community integration in the overall mission of the agency.

Underpinned by a contractual commitment to provide 'replacement units' in local communities, the agency's overall agenda appeared primarily concerned with the establishment, and later the maintenance, of a network of staffed housing, rather than with the actual *content* of the support provided to people living in these houses. For example, documents suggested "following a policy of creating a normal domestic environment" and providing "care and support based *in* ordinary housing." (emphasis added) Any intentions for the content of the service, beyond a commitment to the Five Accomplishments made in the aims and philosophy statements, were not articulated nor operationalised. This caused problems at a direct service level, with the manager of the closing hostel describing progress on closure as being thwarted in part by a "lack of clear guidelines and procedures to put (the agency's) aims and philosophy into action." Added to this, where a principle aim for service content *was* repeated in a number of early documents, it was concerned more with physical presence than social relationships:

> ...to enable (users) to make use of the same facilities and services as their non-handicapped neighbours as far as their individual abilities will allow.

Overall, specific statements or plans to make the philosophy a reality in practice appear far less frequently in the documents collected than plans to make the network of community houses a *physical* reality. Interestingly, citations of O'Brien's Five

Accomplishments, often referred to 'presence' (or the use of community facilities) as the first accomplishment, while 'participation' (or the development of relationship networks) was almost always referred to as the last accomplishment the agency committed itself to pursuing. Some may say the order in which these were listed is irrelevant, or conclude that its unlikely an accomplishment placed farther down the list would imply lesser commitment to it. In defence of the agency, O'Brien himself published the five accomplishments in exactly this order, with presence at the top and participation at the bottom. Whether or not this seemingly prioritised list was reflected in the practice of the agency and its staff remained, at this point, to be seen.

Nonetheless, where the collection of agency documents did discuss the importance of relationships, they demonstrated, albeit peripherally, an understanding of the importance and meaning of relationships which appeared to support the definition of community integration I had developed for this study. The relevant excerpts from these documents demonstrate an awareness of many of the issues which troubled me and ultimately influenced the evolved definition I developed. The documents demonstrated awareness of:

-the problem with having too few relationships & the importance of variety;

-the problem with relationships being temporary or superficial;

-the shortcomings of existing opportunities to develop relationships;

-the importance of close friends and intimate relationships;

-the value of neighbourhood involvement;

-the need for opportunities to form new friendships within one's local community;

-the need to consider the *quality* of relationships with friends, family, and members of the local community; and

-the need to recognise that socially valued roles include that of 'friend' and 'helper'.

Although as pointed out previously, the documents never once referred directly to 'community integration', such attention to the importance of having a network of relationships and positive community involvement clearly supported my position on the meaning and importance of community integration. I therefore took from this that the importance of relationship networks and community integration was well established within the agency's written statements of mission and intent.

2. The staff's position

Staff were asked two things in relation to establishing their view on the importance and meaning of community integration: first, to share their own personal reactions to the evolved definition of community integration developed for this study; and second, to share their insights about the position they felt the agency took in relation to community integration.

Reflections on the agency's position raised concerns similar to that made by the project manager in charge of the hostel closure who was quoted above. The scarcity of available, practical strategies to make the aims and philosophies - particularly, community integration - a reality was clearly seen as problematic by the staff providing direct support to service-users. Although staff's opinions about the agency's position on community integration broadly reflected the content of the agency documents, they tempered their views with a substantial dose of practical experience, which brought home the nature of the gap between the impression created by these documents and the everyday reality of supporting tenants.

In terms of the agency's main purpose, staff consistently identified the provision of community houses and the pursuit of desegregation as the overarching agendas. When questioned about community integration and the development of relationships by those who use its service, staff were less sure of the agency's position. As to where in the agency's written policies or statements there would be evidence of an emphasis on tenants' developing relationships, staff identified the aims and philosophy paper, their own job descriptions, and the future planning tool used by the hostel movers. Some staff however were unsure where they might find such statements, admitting a lack of awareness of the content of these documents:

> I haven't really read the policies that (the agency) puts out, so I'm not sure.

Although most of the staff could identify one or two places where they thought reference to the importance of community integration and relationships might appear, they were uneasy about agreeing that the agency *actively* supported the development of relationships by the individuals who used its service. A number were clear about the agency's support being largely of a tacit nature.

> They encourage the workers to allow this to happen and to promote this...the intentions are there...I think they actively support the idea but its not always easy putting it into practice.

Some staff were however, less convinced that practice evidence demonstrated any level of support from the agency for any agenda. Most agreed the taking anything forward, which the agency supported on paper, was left up to the staff. This "going it alone" perception was consistently reiterated:

> ...my feeling is its very much left up to the integrity of each individual worker to do what's in the best interest of the client...It is actually staff like ourselves that reinforce the (agency's) values; we sort of carry it out or try to...Its the work we do on future planning - that's where we as staff can set up the structures to make sure these things are actually happening.

One staff member clearly took what she saw as the agency's lack of active involvement in shaping practice as a sign that the leadership did not actively support the development of community integration, saying:

> I don't believe (the agency) knows what's going on in the houses. They're not aware of the situation - they are not aware if a (tenant) is sitting around for the next week or if he's got something arranged.

Not only was there a lack of evidence that the agency actively supported its philosophical commitment to tenants developing relationships and increasing their level of community integration, staff were also clear that there was real evidence which suggested that, rather than adopting a position of indifference or neglect, the agency actually took decisions which undermined this agenda. In relation to staffing being available to support the development of relationships, staff commented that additional people were never made available for this sort of work.

> I don't think (they would raise staffing levels to help people develop relationships). They do raise staffing levels for some things, but the only cases where I knew they've raised staffing levels has been on different issues really.

One staff member summarised extremely well the view staff typically held about the agency's concern with community integration, saying:

> There's just no focus on relationship building. Our line managers are more worried about...nothing going wrong than anything going right for tenants. I imagine we'd get more support if it were a crisis situation. But developing relationships for the tenants will probably never be seen as a crisis. How can it?

In contrast to staff's view about the agency position on community integration, staff were asked about the personal views they held: particularly, how they felt about the definition developed for this study. Interestingly, those who raised concerns about the definition did so because they assumed community integration was concerned solely with someone's geographic community. Consequently, some staff were

particularly sceptical about feelings of security being available through one's community.

> I wouldn't confide in my neighbours like I would to my family and friends...I do agree with (the definition) but I would not feel so much that it would have to be people immediately around about me, especially for feelings of security.

When staff were asked where their feelings of security came from, the idea that people's personal relationship networks were more important than their geographic communities was strongly asserted, as was the reality that many people's personal networks are not, or often only partly, made up of people who live in close proximity to them.

> I think that people have relationships with friends, family, partners which will not necessarily be the people who happen to live nearest to you. Most people's experience is that they're scattered over quite a wide area. But I would feel that's where you get your main kind of security from - its your relationships with other people.

As staff began to view community as something that involved both personally-based and locality-based ties, they felt more comfortable with the definition I was introducing. One staff member did recognise however that relationships with those in one's geographic community might be relatively more important to people with learning difficulties, saying:

> I would have thought (relationships with the people in the community where you actually live) would be more important, or more likely to make up the networks of people with learning difficulties because they don't get to meet other people like we do because they are involved in so many segregated things; but for the rest of us, our relationship networks are made up of people who we actually pick out and choose. The number one criteria isn't usually that they live next door.

In addition to local people being recognised as potentially more critical in the lives of those staff supported, most staff also recognised the importance of having a

feeling of belonging and some level of relationship with people who live nearby. Three staff said they had intimate friends who were also neighbours or former neighbours, while two mentioned involvement in local groups as important to their own community integration. Interestingly, two staff recognised that the importance of feelings of belonging may not be immediately obvious, since such feelings are usually taken for granted.

> I'm not particularly aware of having a feeling of belonging, however I think I would be aware of it if I didn't feel I belonged - that would be more apparent to me.

Overall, staff agreed that belonging was likely to be important on three levels:

-as a sign of an absence of rejection where rejection would make most people unhappy;

-as a source of relationships for people who face obstacles to wider socialisation; and

-as necessary to facilitate involvement in community-based groups and activities.

In summary, the importance of relationships, as a source of feelings of security and belonging for staff, was well established. Their comments confirmed that their personal relationship networks played a significant part in each of their lives.

> I don't know if I feel more security or belonging but relationships are a big part of what I feel.

Summary

A clear tension existed between the agency's formal position on community integration, and the implicit messages it then gave to its direct support staff. Despite

this provoking frustration among staff, their views on the importance of relationships in their own personal integration suggested they were a team able to recognise the importance of community integration for those they supported. Still more was learned about this staff team by asking them to consider just how new relationships might be expected to develop.

B. The process of developing new relationships

Introduction

Essential to exploring a concept of community integration that can be advanced through the development of integrating relationship networks, is clarifying an understanding of the process by which new relationships develop. In an effort to establish such an understanding, the ideas of Peter Willmott (1987) on factors essential for new relationship development proved particularly helpful. As mentioned in Chapter Three, in a concise yet pragmatic way, Willmott identifies four factors essential for new relationship development:

1. Opportunities
2. Skills
3. Motivation
4. Mutual Attraction

These four factors were adopted in this study as a framework for discussing and understanding staff's efforts to facilitate the development of relationships by the individuals with intellectual disabilities they supported. To invite staff to think

about their role in facilitating the development of new relationships, staff were introduced to Willmott's model and then asked about their own understanding of how these four factors contribute to the development of new relationships. Once these baseline understandings had been established, staff were asked about their views on how these four factors would be instrumental for people with intellectual disabilities in the process of developing new relationships. The findings from these discussions are summarised here, and add yet another important aspect to the portrait of this staff team.

1. Staff's understanding of Willmott's model

Staff were first asked to comment on what they thought Peter Willmott meant by each of the four broad headings. Through this, people's own assumptions about how new relationships develop were teased out. In terms of opportunities, staff were clear that developing new relationships required opportunities to meet new people, different from those with whom one already has contact. This therefore necessitated not only time for, and access to, increasing opportunities to socialise, but also opportunities which necessarily involved coming into contact with new people. Staff felt these opportunities were likely to be created by extending the variety of places one goes, by doing something new, and by meeting friends of those who are already part of one's network.

For skills, staff recognised that there were a variety of skills that might figure into the development of a new relationship: from the ability to arrange social opportunities and travel to them, to conversational skills that went beyond basic communication skills which would allow people to make themselves understood. Skills important in conversing with others included knowing how to approach

people, initiate and maintain conversation, ask questions, make suitable eye contact and listen well. Staff also recognised that having skills you can talk about (like a hobby or talent) might facilitate mutual attraction and present a basis for initial conversation. More sophisticated were skills thought to be required to avoid doing something to embarrass the other person, and to be able to recognise who is showing an interest and therefore might be worth trying to get to know better.

In terms of motivation, staff said motivation to develop new relationships was important in a number of ways. Initially, one must want to go out and socialise, and want a new relationship to develop from this. In addition, one's motivation would be reflected in the interest shown toward other people and one's desire to speak to others in a social situation. One staff member felt having something in common with another person might make motivation increase after initial contact had been established.

Finally, on the subject of mutual attraction, although staff said it was more difficult to define, they generally agreed it was an essential ingredient for any new relationship. People described it as "something that draws you to another person" or "a gut instinct about whether you like or don't like a particular person." People felt mutual attraction was often determined by how one reacted to what another person was saying - in particular, whether one found it easy to empathise with another person's values and beliefs. Others thought initially, mutual attraction might be determined by simple physical attraction.

When prompted, staff collectively demonstrated a substantial level of understanding about the sociological processes underpinning new relationship development. They generally agreed all four factors were inter-related although people had slightly

varying views on how these four actually came together to form the basis for a new relationship. Staff were divided over which single factor they considered most important, with half saying opportunities, and the other half saying mutual attraction. Just one said skills were most important. Overall, while staff demonstrated a thoughtful awareness of the ways in which new relationships were likely to develop, the views outlined above were largely the result of staff relying on their own personal experiences. When asked to consider Willmott's four factors for the people with intellectual disabilities they supported, their perspectives changed somewhat.

2. Applying Willmott's model to people with intellectual disabilities

The majority of staff thought opportunities and skills were the key to making new relationship development possible for the intellectually disabled people they supported. Opportunities mentioned included greater opportunities to come into contact with new people:

> They don't have the same opportunities to meet people that I have...(They) leave here on the centre bus and go straight to the centre. Again, its people they already know, and then back home on the same bus with the same people.

Another staff member commented that they struggled to identify these opportunities:

> They don't know anybody or any places around here, we've got to find them.

This comment illustrated the challenges involved in moving to an unfamiliar place where the people with whom one already has relationships don't know the area either: namely staff. Additional concerns were raised about staff. One staff member felt that people's security with staff could lead to tenants becoming

inappropriately secure and therefore unmotivated to pursue opportunities to develop new relationships.

> I think maybe they feel they've got (a network of relationships) here...I think they'd probably say staff are friends but I think the more people they knew who weren't paid to support them, the more obvious the difference between them and staff would be. You know, they only have staff and the people who used to live at (the hostel), who they would call friends, but who are really only in their lives because they were forced to live together.

While one staff member thought this scenario should be accepted, saying:

> I think sometimes people with learning difficulties are forced into trying to make relationships when they...don't particularly want to...when for the most part, they are quite happy with their current circle of relationships, most of that being staff and family.

...most staff thought this scenario was unsatisfactory:

> Its fine saying they can turn to staff, but they need other people outside that world...they need someone they can pick up the phone and say I'm fed up, can we get together - like we would do. Staff aren't going to stay around, I mean situations change in life. When it comes down to it, this sounds really cruel, we're providing a service and also a service for ourselves. We are put here, although we choose who we want in our homes, this is put upon them.

A similar point was made by another staff member, stressing the fact that although 'forced' networks are not ideal, while they have nothing else, they rely on them for security.

> Well I think people do have a network of relationships, its just not the one they've chosen - its the other residents and the staff. The point is that they didn't choose those particular people. But to some extent, they derive their support from that, nonetheless.

While it may ultimately be debatable whether feelings of security drawn from relationships that are not necessarily chosen represent a satisfactory scenario, it does seem clear that this staff team recognised that those they supported would not have

an alternative source of security unless other new or existing freely chosen relationships are fostered. One staff member suggested what may be the crux of the problem, saying "its too easy to get into a routine of coming home, getting off the bus, and making a coffee," where staff and tenants alike collude in reinforcing this.

Yet beyond the need to widen opportunities, staff also felt strongly that skills were a second key to the successful development of new relationships by those they supported. Only one staff member thought the presence of mutual attraction would eliminate the need for skills, while the majority of staff seemed to feel mutual attraction for people with intellectual disabilities would be dependent at least in part on their level of social skills. However, a number of staff saw a clear link between having opportunities to socialise and the successful mastery of social skills necessary to develop new relationships.

> I think they also need more opportunities because its probably not something that they're used to - going out, meeting people, trying to make friends. The more they are able to go out and do it, then hopefully the easier it will become...If they've got no opportunities then they've not got the chance to try out their skills.

Another staff member argued for increased opportunities in order to facilitate the development of social skills by concluding that opportunities could increase the things people had to talk about.

> I think its difficult for people who have limited things to talk about - limited experiences to actually talk about to develop conversational skills. And it makes it very difficult. I think its hard to form any kind of relationship if there's really severe limits on that kind of thing - if you can only keep saying the same things over and over again.

Summary

In retrospect, staff proved highly intuitive about the nature of new relationship development processes, and they came out universally in favour of opportunities to meet new people as the most critical factor in facilitating the development of new relationships. In addition however, a clear concern with the development of social skills was expressed in relation to the intellectually disabled people they support. In order to move forward into a discussion of the activities of this staff team and the outcomes these appeared to generate for tenants, the position of the agency and this staff team must be clarified on one final subject: their views on the role (and more implicitly, the responsibilities) of direct support staff in facilitating community integration outcomes. This subject is discussed by way of closing out this first chapter of the study's findings.

C. The role of direct support staff in facilitating community integration and new relationships

With an apparent recognition among staff about the fact that their own relationships with tenants were inadequate alternatives to a freely chosen network of relationships, the role of staff in facilitating such relationships became a critical issue to consider prior to considering what new relationship development actually occurred for those supported.

1. The agency's position

Looking again at the documents collected, the role of staff was most directly addressed in the job description of the direct support staff member (called 'core

worker'). This description reflected the agenda outlined in the aims and philosophy statement of the agency, and identified staff's general duties as assisting tenants to achieve the Five Accomplishments. In addition, the job profile emphasised three key goals:

> -to help create a real home life,
>
> -to promote real friendships, and
>
> -to work toward securing a real place in the community for the people living in the house (s) in which [staff] work.

In addition, "planning and carrying out daily and weekly programmes of activity" and "balancing responsibility for the safety and well-being of tenants with the need to promote a valued and positive life experience" set out a limited framework in which staff were expected to work to pursue the above goals.

2. The staff's impression of the agency view on their role in facilitating community integration

The limited amount of guidance the agency appeared to provide with regard to the specific role of support staff, left those involved in this study with the task of augmenting a rather brief job description with their own impressions of the agency's expectations of them, based largely on practical experience. This did not always prove easy, and a number of staff questioned not only what the agency expected of them in their role, but why they were hired initially.

> I've often looked at everybody (working as core workers) and thought why are we all here...why were we hired. I don't know what the criteria is that they're looking for... I assume they're just looking for a reasonably broad-based person that's got a lot of ordinary skills.

Adding to this confusion over the basis for their recruitment, staff's awareness of their job description varied widely, with 25% saying facilitating and promoting relationships was definitely in their job description, another 25% saying they thought it was but weren't sure, a third 25% saying they didn't have any idea what was in their job description, and the final 25% not even mentioning their job description as a potential source of guidance on their role in facilitating and promoting relationships.

In contrast, staff had much to say about whether, in their view, the agency supports the idea that helping tenants develop relationships was a priority for its core workers. They seemed much more certain of what the agency *did not* consider a significant part of their role than what the agency *did*.

> The priority seems to be to get the tenants out and about, but it's not so much about developing relationships as it is about activities.

Another staff disagreed that involvement in community activities was even the priority, saying:

> To (the agency) it's obviously okay that we spend most of our time on domestic work because nothing else has been done about it to enable that to become different...but I don't think they'd ever admit to saying that's okay though.

Interestingly, one staff member noted that the agency seemed more concerned with setting up additional houses than with what was going on in the houses already up and running:

> There's so many other things requiring (the agency's) attention in terms of actually moving people out...I think it's assumed that we are doing it. If we weren't, they'd all go 'oh, but why aren't you?'. I think the people higher up are not focused right down on individuals.

In discussing relationship-building in particular, staff gradually moved into articulating a feeling that they were very much "going it alone" in their work. In terms of promoting or facilitating relationships, one staff member reiterated the idea that the agency's management wasn't involved in determining what happens everyday for tenants, saying:

> I think (the management) let it up to staff to decide what our priorities should be. Developing relationships is difficult...

In general, staff consistently commented:

> I (no one else) remind myself of what I'm meant to be doing ...Really, I just know what I think I should do. No one ever asked me to relate my work to (the agency's) policies. In practice (the agency) employs staff and its up to the staff to see where help is needed and give that help (to tenants).

Significantly, other staff were more aware of their shortcomings, recognising that in some ways, because the agency left the priority-setting up to staff, there was a potential for things to be different if staff wanted them to be different:

> Nobody above project leader level has ever...said how we could go about making (relationship development) happen, *but I suppose we could if we really wanted to...* (emphasis added)

In addition, while the majority of staff were critical of the amount of support and guidance they received from their supervisor, one staff member recognised that where advice was given on pursuing community integration, the staff seemed to struggle to take it on board.

> She does encourage us to go out...She could come along and say to us its okay to leave a sink full of dishes if you want to go out - I think she has done it on occasion, not in so many words but...she should maybe come along more often and reiterate that because half of the staff don't feel happy in ourselves about leaving dirty dishes and the other half don't feel happy about leaving them because the person on the next shift will be coming in to them...But give the project leader her due, she has said these kind of things - its obviously not sinking in.

Another staff member made a similar point, albeit in a rather round-about way, emphasising the fact that staff bring their own values and standards into their work in some areas, and therefore make more proactive efforts in these areas.

Staff: There's always been quite an emphasis on opportunities in terms of trying to arrange things for people, particularly things that are not segregated...that's always been fairly strong (from the agency) and that's the thing that staff have taken on board a lot. To actually motivate someone to form a relationship with other people is difficult. And to some extent there's a kind of conflict there with a "let people do what they want" ethos.

Researcher: So what would be the agency's position on this issue of people developing relationships? Would they come out stronger on choice or on motivating people?

Staff: I would have thought they'd come out stronger on choice. But in terms of mutual attraction, I mean most staff naturally do encourage people to enhance their attractiveness. I don't know if you actually need to have an agency policy on this, except in terms of discouraging...I mean the agency wouldn't approve of people being dressed in inappropriate ways.

Researcher: So on the issue of appearance, would the agency fall on the side of choice again?

Staff: No, I think on this issue the agency probably would fall more on the side of a greater degree of direction rather than choice. But generally speaking staff tend to bring their own standards in a lot on that and would be providing that direction anyway. So the agency really doesn't have to take a position.

Clearly, where staff decide certain standards should apply, either because the agency makes that clear or because staff as individuals believe they should, this results in more proactive and "directive" staff support of tenants, with the choice to say no viewed as less appropriate to accept. One staff member was quite blunt about this reality, saying:

> The (tenants) have been controlled all their lives by others. Now, its not as obvious but its still happening; they are being controlled now more invisibly. Its done more tactfully - called persuasion - its done in a way that its made to look like (the tenant's) idea. Its control through suggestion really.

Perhaps, staff hold less strong views (for what specific reason it is hard to determine at this point) about the importance of tenants pursuing the development of new relationships and therefore are less directive in their approach, allowing tenants' choices to guide the support they provide in this regard. Some may say this choice should be respected. Yet, if choice is truly being respected on the issue of developing relationships, the choice by tenants to pursue new relationship would also be respected and staff would consequently change their priorities accordingly. Yet, it is this aspect of choice that it seems may not have been responded to in practice. And one can imagine a scenario where staff's inability or perhaps unwillingness to put the development of relationships at the top of the priority list, could be avoided by making the assumption that tenants do not really want to pursue new relationships. Regardless, staff generally agreed that their own values and standards influenced the way they supported tenants.

3. Staff's personal view on their role in promoting and facilitating community integration

While the poignant examples cited above, in which two staff suggested that the focus of individual team members' support to tenants was likely to be guided by personal values, were indeed concerning, when staff were asked about what they felt was their most important role, the extent to which their own values and standards actually *did* determine this became even more clear.

First, the extent to which staff use a reductionist approach to defining the priorities of their job was vividly conveyed by one staff member who simply said:

> I think our most basic role is actually ensuring people are fed and clothed and still alive at the end of a shift...that you hand over live bodies to the next person coming on.

Beyond this, staff thought they should be concerned with two general areas:

> -having a good relationship with the tenants that cause them to feel secure, trust staff, and to feel content with their lives; and
>
> -improving tenants' functional skills to promote independence and conversational skills to promote social competence.

Two staff identified a key part of their role as being a friend to tenants: one said "I want to be like their friend but that's not easy...we know we are paid to care for them and look after them so that makes it difficult. Another staff felt a significant part of 'being a friend' to those she supported was "to give them a feeling of security and build up a trusting relationship." For other staff, helping tenants improve their skills was paramount, to enable them to become more independent. All staff generally agreed that improving skills was the key to tenants' growth, emphasising a medical model approach to improving people's lives and facilitating greater social acceptance.

> I try to provide a certain amount of encouragement and show people what's appropriate behaviour in social settings...We try to get people to see the tenants in their best possible light, and this is about encouraging the right social skills, appropriate behaviour, and appearance. If these things aren't attended to, you know, it can make other people feel uncomfortable.

One staff member suggested that she felt there was a sequence in which skills should be learned, saying:

> I think (our priorities) should lie with people being able to get out and about and meet people to form relationships; but then I don't really know on that one - I think that's maybe a case of running before you can walk...I think in life you progress step-by-step.

Although this person wasn't advocating a complete "earn-your-way-to-community integration" model, her comments did suggest that learning and practising personal

care and household skills should not be sacrificed or pre-empted by attempts to promote community integration. In this, what was and was not expendable became clear. Such a position reinforced evidence introduced in the previous section that suggests staff are guided in their work by their own personal values and standards. A similar view was also shared by another member of staff, implying an implicit priorities list existed not only among the agency's leadership but also among the staff team. He offered his personal view, saying:

> (relationship development) is bound to be taking second place to the everyday aspects of the job like ensuring people's safety and making sure they get fed and get their housework done... those things to some extent won't wait while working on relationships is the kind of thing that can always be put off to another time.

Chapter Conclusion

The above quote demonstrates, more than anything, this staff member's apparent unflinching acceptance of this established hierarchy of need. Where Maslow (1954) may well agree with personal safety and the provision of food coming before relationship building, one can hardly find mention of housework in his famous hierarchy of needs! Such a position is quite similar to the critical comment by another staff member quoted earlier in the chapter but recounted here:

> There's just no focus on relationship building...I imagine we'd get more support if it were a crisis situation. But developing relationships for the tenants will probably never be seen as a crisis. How can it?

These findings only reinforce and illuminate what existing literature states about the critical role that staff have to play in community integration outcomes. Yet perhaps these findings suggest a new and slightly different emphasis. Instead of focusing upon the potential of staff to positively affect community integration outcomes, these quotes and the bulk of this chapter begin to suggest how staff can create a barrier to the development of positive community integration for those they support. Clearly staff's own standards and priorities influence significantly the support they provide. This chapter allows one to begin to see why.

On first look, one finds an agency that has established a positive and principled mission in relation to community integration and the importance of relationships. Yet closer inspection reveals it has failed, both to translate this mission into specific plans for action at a direct support level, and to implant a serious concern for these issues in the minds of its direct support staff. Although staff added to this lack of firm direction with their cynicism about the extent of neighbourhood involvement that is actually realistic and indeed 'normative', they did however recognise - when prompted - that their own lives were significantly affected by the relationships they had, both with local people, as well as with friends and family.

Even more positive still seemed to be their ability to understand the complex nature of relationship development. What Willmott's theory enabled staff to do was to explore their own views on what would actually be involved in facilitating a new relationship for those they support: in other words, to identify what active agendas might contribute to such developments. Where the agency had failed to give such guidelines, staff were prompted to explore their own understanding of what is a very complex sociological process and they proved themselves to be far from ignorant.

The overall portrait of this staff which has evolved in this chapter, illustrates a group of individuals who realised somewhere, on paper at least, that the agency which employed them supported the need for tenants to develop positive relationships that would extend beyond those with staff and other tenants. They were also a staff team who appeared to recognise the importance of relationships in their own personal lives, and were able to see the parallels between themselves and those they supported in this area. And finally, they were a staff team who had the capacity to generate a somewhat sophisticated understanding of how new relationships develop, and to recognise the specific issues within this that created additional challenges for people with intellectual disabilities. Yet clearly, since staff were *going it alone*, often confused and disheartened by the agency's limited involvement with them in their attempts to put community care into practice, their own personal agendas seemed to take precedence and their commitment to proactivity in certain areas was sharply contrasted by indifference and perhaps inactivity in other areas. Its seems almost too simple to conclude that where they came out in favour of tenant choice, this simply implied their indifference to the issue at hand. Yet this may prove to be the most accurate explanation.

Nonetheless, despite *going it alone* giving staff a clear ability to influence what they did on a day-to-day basis, one cannot deny the evidence of the agency's implicit expectations and the limitations which have been imposed on staff as a consequence of the agency's overall approach. However, teasing out how this mix of factors is related to actual developments (or lack thereof), in the area of relationship networks and community integration for those being supported, is the next step in this study's attempt to determine how direct support staff impact upon the community

integration outcomes of those they support. Despite the many issues raised in this chapter, one staff member still concludes:

> While I believe it's still very much left up to the individual team member and the actual team to always look after the client - and do your job in the correct way, I think in this particular team, we do encourage each other to [work on relationship building] as much as we can.

Whether evidence of actual practice reinforces or contradicts this statement remains to be seen, as do the community integration outcomes that develop for those whom the staff team support. Before moving on to the evidence about the role of staff, the next chapter addresses the community integration outcomes that developed for the intellectually disabled people being supported.

CHAPTER SEVEN

"Relationship Network & Community Integration Outcomes"

Chapter Overview

This chapter presents portraits of the three individuals with intellectual disabilities at the centre of this study, illustrating both graphically and through qualitative discussion, the nature of their relationship networks and experiences of community integration during the post-move period considered.

Introduction

For reasons stated previously, this study has focused upon the pattern of *post-move* development in people's relationship networks and resultant community integration, rather than undertaking a more limited comparison between pre-move and initial post-move data. Consequently, four post-move data collection points exist, collectively spanning 2 1/2 years, which offer significant insight into growth related to *community living* as opposed to growth related to *relocation.* For reference, the four post-move data collection points were:

1) 4-7 months 2) 9-12 months 3) 19-22 months 4) 27-30 months

It is important to state at the outset that summarising the development of three individuals' community integration over a nearly three year period has proven a daunting task that required concise explanation and selective inclusion of supporting evidence which would bring life to the explanation. In doing this, I first created four separate post-move portraits for each individual, each of which reflected the findings at the corresponding data collection point. I then used this series of time-specific portraits as a reference for creating a single thumbnail portrait of each individual which, although brief, captures the nature and extent of the changes that occurred over the period of observation. To avoid excessive length, the thumbnail portraits compare the findings from post-move data point one with those from data point four: a strategy which demonstrates the developments that ultimately occurred over the 2 1/2 year period. In particular, I consider the sources of both feelings of security and belonging that existed at the first post-move point, and how these manifestations of community integration had changed or developed 2 1/2 years later.

As I said in Chapter Five, I have been concerned primarily with staff's interpretations of these individuals' relationship network outcomes; thus much of the evidence drawn on has been staff interviews, which include the relationship networks created by each staff member at the post-move points considered. To determine whether staff's interpretations of these individuals' relationships were grounded in reality, I have also drawn on the diaries and interviews of the intellectually disabled individuals' that were completed around these post-move points.

Gary

Gary was consistently described by staff as a very sociable character who is friendly with everyone. Gary's motivation to get out and socialise complemented his friendly personality, making him neither shy nor reluctant to meet and socialise with others.

> He is basically a very friendly, outgoing, likeable chap. He makes himself likeable intentionally...he tries hard because he knows that is a way of making friends.

Gary generally got on well with other intellectually disabled people and staff. He showed no animosity toward any particular people because of their 'position.' Early on however, staff noted that despite Gary's positive personality, he didn't have as many friendships as he wanted, and could therefore feel bored or lonely at times. Staff cited evidence of this.

> I think he enjoys [sitting alone in his room] but if he had something else to do like going out, I think he would prefer to do that.

Gary's initial relationship network

Figure One illustrates Gary's first post-move network, compiled just a few months after the move. Gary's friends were all people he had lived with in the hostel prior to the move. Janet moved to a group home in a nearby town, while Ralph shared Gary's new flat, and Roger lived in a flat opposite them. Five relatives figured prominently in this early network. Staff agreed that Gary's move, to the district

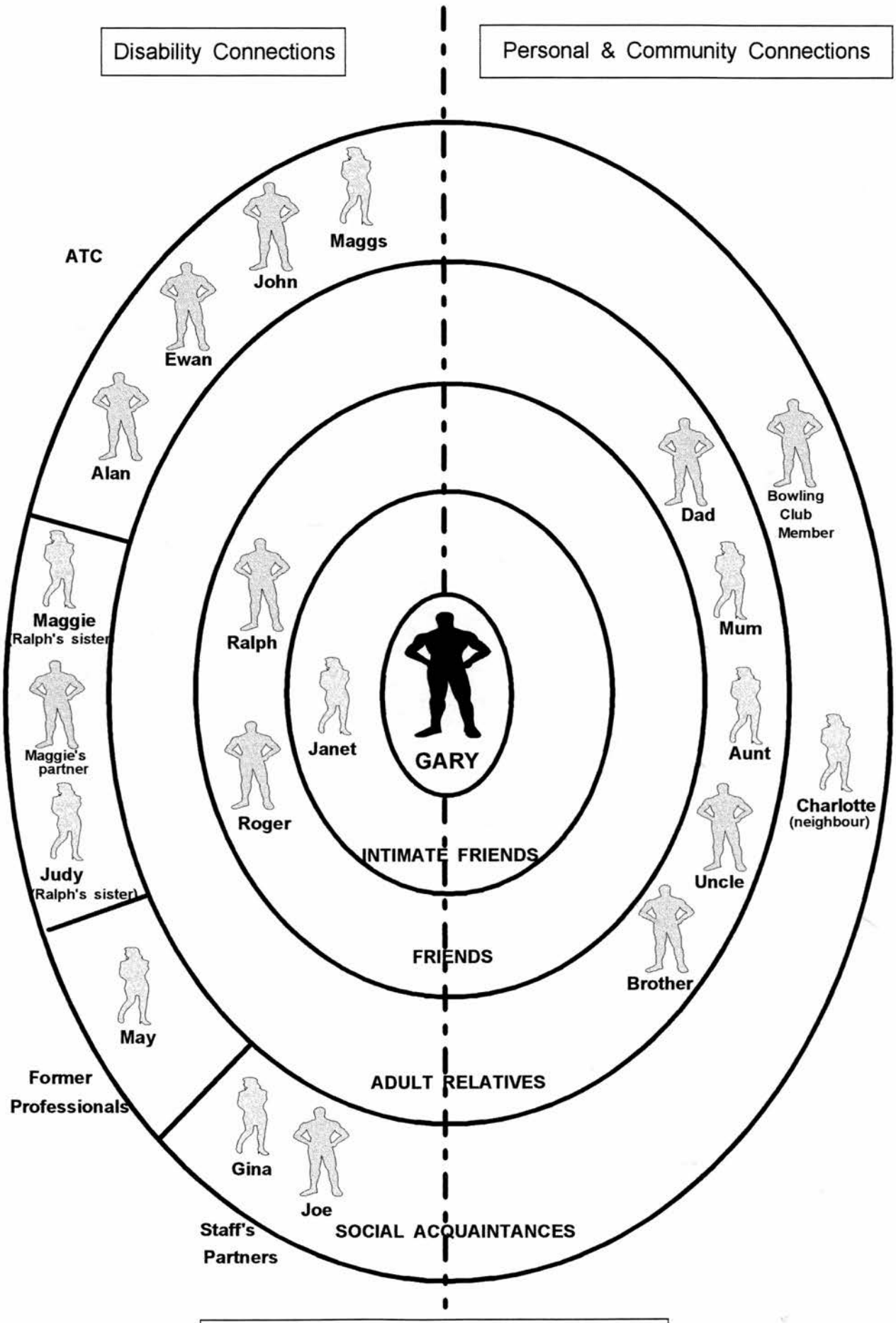


Figure One: First Post-Move Network

where his parents lived, was critical to improving their relationship.

> I think Gary's relationship with his family is quite different now. His parents see him every week and they are always phoning each other...He's regularly at home to visit and his brother took him on a weeks' holiday recently; there's a real love in that family, and a love for Gary.

Twelve social acquaintances also appeared in Gary's first post-move network. Four were people with intellectual disabilities whom Gary typically met at the adult training centre (ATC) he attended four days each week. The other eight were people without intellectual disabilities: Figure One shows two were community based, while six were disability-based acquaintances.

The status of Gary's initial relationships: 2 1/2 years on

While Figure Two demonstrates that Gary's intimate friendship with Janet declined significantly, it fails to show that Gary's friendships with Ralph and Roger also declined in quality, although staff did not feel they had become acquaintances. Evidence suggests that all three relationships declined, not for lack of contact, but because they could no longer get along as friends. Early on, staff noted that Janet did not consistently value her relationship with Gary.

> I think Janet actually ignores Gary from what I can gather - not all the time but he will come back (from the ATC) saying Janet wasn't speaking to me today.

Over time, staff recognised that Gary began to act similarly toward Janet.

> Gary gets quite fed up with Janet now when they are together here. He will sometimes go into his room and ignore Janet.

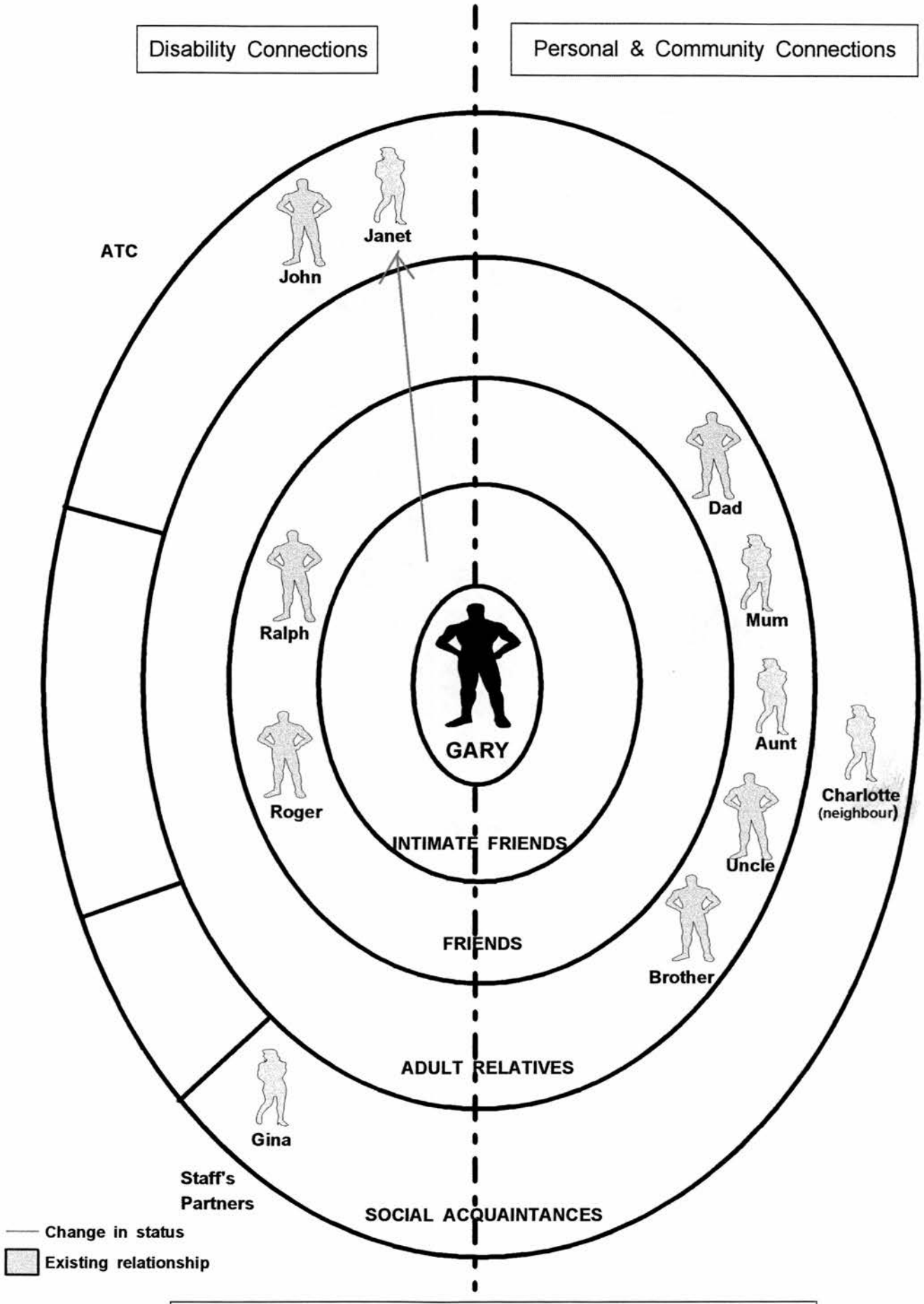


Figure Two: First Post-Move Network - 2 1/2 Years On

As time passed, Gary and Janet's contact beyond the ATC ceased. Gary's final diary confirmed one staff's observation that "[Janet's] definitely out of favour now. He just doesn't talk about her...There's something about Janet that's just not the future for Gary."

Meanwhile, staff observed that Gary's relationship with his flatmate Ralph was becoming increasingly strained as time passed.

> ...when you see somebody making a fuss over Gary - Ralph will hover about as if he's waiting for a chance to jump in and say make a fuss of me...there's a huge rivalry there.

Rivalry was ultimately replaced by outward signs of rejection developing between Gary and Ralph.

> Gary is really impatient with Ralph...the whole arrangement is rather artificial - here is a young middle-aged man...who suddenly gets a place in this flat with Ralph...they are not suited as flatmates basically... the tolerance is now so low.

Similarly, Gary's early friendship with Roger was also undermined by rivalry in the end. Although staff were initially convinced this relationship was actively chosen, and it quickly grew into an intimate friendship, Gary's final post-move network revealed staff felt the relationship had slipped back to just friendship. Evidence suggests it may have deteriorated beyond friendship. Early on, the diaries showed Gary and Roger spending time together daily. Yet as time passed, Gary began to show that he wanted less contact with Roger.

> Sometimes Gary will invite Roger over and then he'll shut himself in his bedroom and never answer the door.

Although nineteen months on, they were still spending many evenings together, evidence began to demonstrate that their relationship was becoming increasingly strained.

> There is a fierce rivalry [between them] in the community now. Roger has always gone out for walks in the community and wanders round and chats to people. Now Gary has started doing that and they have been 'stepping on each other's toes'. I think that is partly why there is animosity between them now. It is like a couple of tomcats. I have witnessed a verbal assault which they had on each other outside the local shop...I mean it was really nasty...Roger sort of accosted Gary for talking to these two young lasses. There was this great big bust-up between them. But it has happened on a number of occasions...

In the end, staff concluded that Gary's friendships had not evolved naturally but seemed rather to have come about due to a lack of other alternatives, and therefore were not able to stand the test of time. Meanwhile, throughout the post-move period, staff agreed that Gary's relationship with his parents was the strong point in his relationship network, and Gary's diaries continued to show a regular pattern of contact.

> Gary has very regular contact with his parents - one comes every weekend and takes him out unless there's some reason to prevent it...Its also not an unusual occurrence for Gary to go and spend the weekend with them.

The diaries also showed however, that Gary's pattern of contact with his parents had reached an early plateau, changing little over the longer term post-move period. This lack of change in the nature of these relationships suggested they would offer little *more* to Gary's life in the future. Staff also recognised that Gary's relationships with other family members needed to become stronger. Yet evidence suggests these family relationships did not escalate to include more significant patterns of contact

or interaction. Other family members typically had contact with Gary only when he saw his parents.

Of the twelve acquaintances listed in Gary's first post-move network, Figure Two shows only three were retained while nine were lost. Early on, Gary's diaries revealed that all of these acquaintances were generally consequential relationships, where Gary's contact with them resulted from something other than direct intentions to be together. The fact that the majority were lost makes sense given this context. Of those acquaintances that remained in Gary's network, none became anything more than acquaintances. In particular, this was the case with Gary's neighbour, Charlotte. While the first diary showed, over a six-week period, they had one meeting, the final diary 2 1/2 years on, showed this pattern had changed little.

New developments in Gary's relationship network

Given that Gary's friendships at the time of the move had all declined significantly after 2 1/2 years, it is important to understand what new relationships developed to fill this and previously existing voids in Gary's life. Figure Three shows two new intimate friendships developed within the 2 1/2 years considered. One, with Jason, developed early on when he was matched with Gary through the agency's volunteer programme. The second evolved much later where a positive rapport developed at the ATC with Liza, and, at Gary's request, this was supported to develop . Figure Three also shows that Gary established contact with five additional relatives, and eight new social acquaintances.

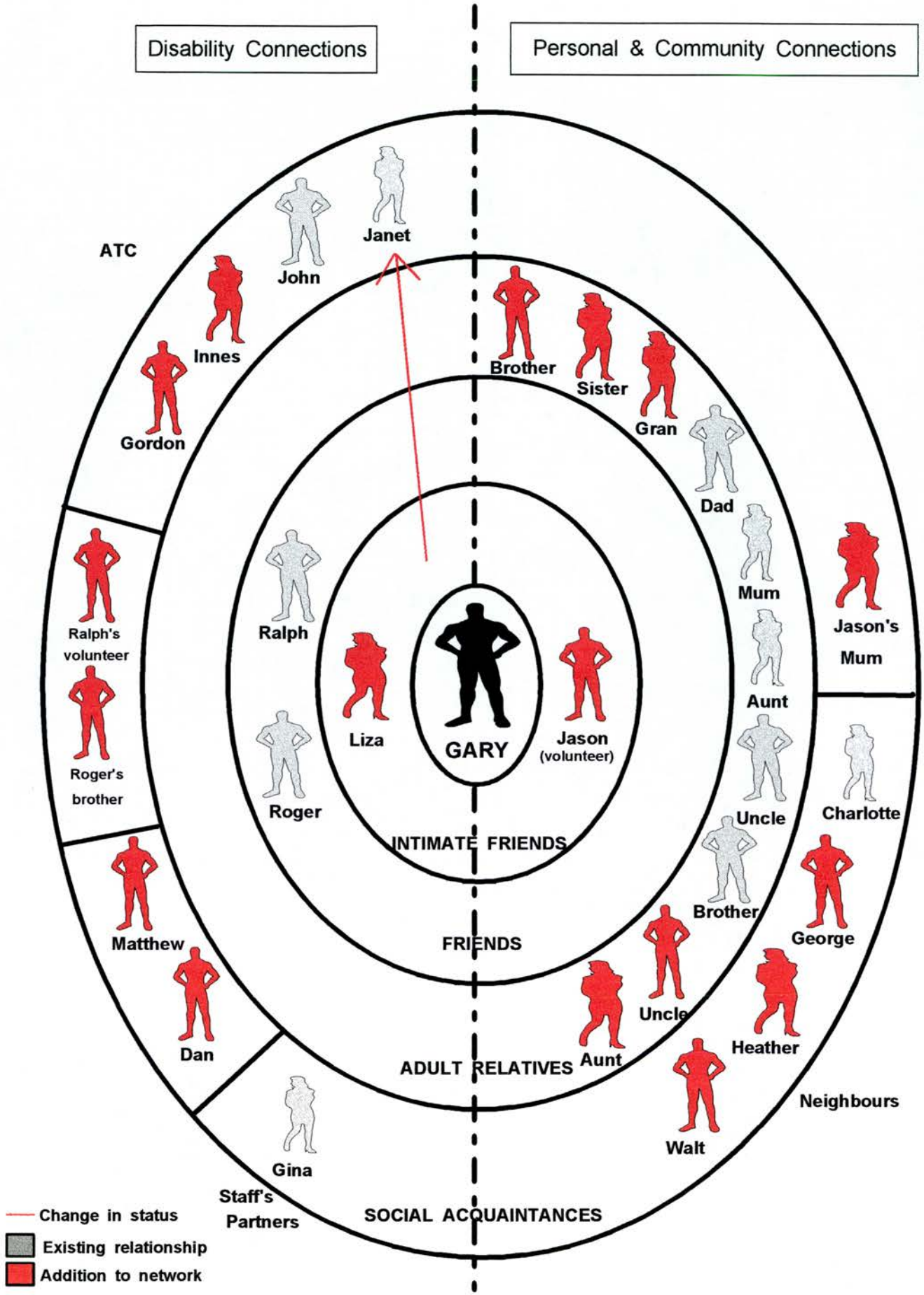


Figure Three: Final Post-Move Network - 2 1/2 Years After the Move

Although Figure Three reveals that Gary's net gain in intimate friendships was only one, what Figure Three fails to show is that the nature of Gary's new intimate friendships seemed to be more healthy than the relationship he had initially had with Janet. However, some uncomfortable circumstances arose in Gary's relationship with his volunteer. While staff agreed that Jason was a positive addition to Gary's life, Jason soon became a member of staff in another group home, which had a negative effect on the friendship.

> I don't really think Gary likes [the fact that Jason is a staff member]. This week, when Jason came, he had tenants with him from the house where he works because he was on shift there. And while it used to be very much that Jason came here just to get Gary or visit him, now he will chat with us about work...Gary probably thinks 'wait a minute, this is my person.'

Over time, Jason's role as staff member and volunteer continued to overlap. Once, Jason did a pool shift at Gary and Ralph's flat. Despite these issues, staff thought his relationship with Gary grew into an intimate friendship.

> Gary's relationship with Jason has increased in significance, they've gotten closer, there's more contact, you know regular phoning back and forth.

2 1/2 years on, Jason had been in Gary's life for two years, and staff agreed this relationship was likely to continue. Yet staff still had reservations about Jason's role as a paid worker.

> Jason is constant, conscientious - reliable about his duty, but I see it as a duty with him. I think the problem ...is that Jason works for (the agency)...(it would be) fresher and much less cluttered if he didn't.

Gary's relationship with Liza, although developing much later, came about in a

much less structured way, and staff recognised the genuine affinity between them.

> You can see they obviously just click in terms of their shared sense of humour - they just really have a good laugh together.

Most staff agreed Liza and Gary were intimate friends, although the time they shared together was sometimes limited by circumstances outwith their control.

> ...for a while Liza wasn't staying at the short-stay house. Then there was a bit of confusion about whether Liza's dad wanted Gary to visit her when she was at the short-stay house...by the time that was cleared up, the short-stay house was fully booked, so Liza wasn't there again for a while.

Gary's last diary showed frequent contact between he and Liza when she stayed at the short-stay house, including Gary phoning Liza often. Staff reported that sometimes Gary invited Liza for tea and once or twice they had gone to the local Labour club for a drink.

Meanwhile, Gary expanded the number of relatives with whom he had contact. 2 1/2 years after the move, Gary had new contact with a second brother, his sister, his grandmother, and another aunt & uncle. However, few of these relatives, particularly his sister and brother who lived locally, had contact with Gary outwith the regular time he already spent with his parents.

Of the social acquaintances who were additions to Gary's network, the two people with intellectual disabilities had no real interest in Gary, nor did he in them.

> Matthew & Dan wouldn't be anything more than social acquaintances to Gary. He only sees them when they come here with Jason.

Similarly, Roger's brother and Ralph's volunteer had no contact with Gary other than when they came to visit Roger or Ralph respectively. This *consequential* contact was also the case with Jason's mum.

> Gary' is pretty chatty with her on the phone...its slightly more than a social acquaintance but not a friend. He's been there for tea with Jason quite a few times.

In terms of neighbours, while the relationship with Charlotte did not improve over time, because it was sustained, Gary also became friendly with Charlotte's husband George. As time passed however, their relationship did not develop.

> Charlotte and George are only being nice because they are doing a service to the neighbourhood - she's the warden around here...The men have been invited to barbecues and other things - that's them being friendly, they invite all the neighbours.

Another neighbouring couple, Heather and Walt, were added to Gary's network, although the same type of contact existed. They were simply 'friendly' with Gary.

Reflecting upon Gary's relationship network: 2 1/2 years after the move

The previous discussion clearly demonstrates that, other than in the adult relative category, there was little *net* growth in Gary's network once the additions were offset by the losses from the initial network. Over a period of 2 1/2 years, Gary's initial friendships and family relationships either declined (friends), or stayed the same (family). The majority of existing acquaintances were lost. Of those remaining, like family, none became a more significant part of Gary's life over the period of time considered.

The two new friendships that developed into intimate friendships were clearly more positive than those Gary had initially. Yet both involved fundamental difficulties which clouded the further development of these relationships. And although family contact was extended to double the number of relatives in Gary's network, his parents remained the most significantly involved. The new acquaintances that replaced those lost were largely people who became Gary's acquaintances through relationships Gary already had. Unfortunately, if past outcomes are anything to go by, it is unlikely these people could be expected to become any more than acquaintances to Gary in the future.

Community integration outcomes for Gary

The balance of relationships in Gary's first post-move network, did not seem right for a middle-aged man. Where friends might have been expected to complement relationships with family, Gary's life was dominated by the presence of, and his reliance upon, professionals. A list of scenarios where *practical* assistance would be needed revealed that staff felt Gary would consistently turn to them or other professionals, rather than to friends or family. For scenarios where *emotional* assistance was required, staff concluded Gary would be likely to turn to his parents and staff, rather than to friends.

> Gary's not got many people beyond staff and family and the other two tenants who live here; he's got no friends in the community. He depends a lot on the staff team here.

In terms of community integration, staff concluded that Gary got his feelings of security from his parents and the staff team supporting him at his flat. None of the

staff felt Gary's intimate friends and friends were a significant source of security for him.

> I think they are important, but I think they add to Gary's feelings of security rather than providing it.

In terms of belonging, Gary had positive yet limited contact with neighbours and other community members. Staff agreed Gary was beginning to experience a sense of belonging about the community to which he had moved.

Yet 2 1/2 years on, Gary's sources of security had changed little.

> Well, the people who are most significant to Gary are his mum and dad and staff here...

Although outwardly, Gary's relationships with Jason and Liza were indeed positive, because of the limited contact that characterised these relationships, they played little role in providing Gary with feelings of security.

Gary's diaries confirmed that few people, apart from staff and family, figured in his life in any significant way. Although Gary had formed positive acquaintance relationships with some neighbours which provided his feelings of belonging, Gary's relationship network continued to lack any significant new sources of security. Despite staff's assumption that Gary's personality should make it easier for him to make friends, and indeed their agreement that he desired more close friendships, Gary's circle of intimate friends and friends began and remained small throughout the observed period.

Roger

Roger was described as a social creature who likes being amongst company and takes an interest in people, while also enjoying his own company at times. At the first post-move point, most staff thought Roger was unsatisfied with his network and would have welcomed new opportunities to extend this.

> [Roger] quite likes being on his own but if other people were there, he might do something else rather than just watch the same [videos] over and over.

It seemed however that Roger was cautious in developing new relationships, and therefore "quiet at first meeting people, sometimes just clamming up." According to one staff member, Roger did not previously have a particularly good relationship with staff, often seeing them as people to be outwitted, which may have explained his cautious approach. However, staff agreed his attitude toward them had improved greatly since the move, which made him more likely to confide in the staff who supported him. Roger also showed generally positive feelings toward other people with intellectual disabilities, and a willingness to develop relationships with them. In addition, he showed no apprehension in getting to know his neighbours.

> Roger stands at his back door quite a lot in the summer, so anybody that is coming along will speak to him. If Roger sees one of his neighbours in their garden or fixing their car, he gets his tools and joins them...that's the way he makes friends, Roger gets in beside them and tries to help.

Early on, staff felt Roger was likely to experience loneliness, and cited his pattern of phoning or visiting Gary and Ralph's flat (where staff were also based) as evidence of this.

> I sometimes wonder if Roger coming across...every night is for the right reasons. I wonder if Roger isn't getting the company that he needs.

Roger's initial relationship network

In Roger's first post-move network (Figure Four), staff consistently identified five significant friendships, all of which were with other intellectually disabled people who had lived at the hostel with him. Ewan and Jane moved to a group home in a nearby town. Ralph and Gary lived in the flat across the road from Roger. Gavin moved to another group home in a nearby town.

In terms of family, Roger's brother was central, while he also had established contact with his niece Wanda, and her husband, Bob. Over twenty acquaintances were also listed in Roger's network. These included people Roger typically saw at the ATC (7), relatives of Ralph and Gary (4), a staff member's partner, a number of Roger's neighbours (5), and two volunteer co-ordinators at the local day centre where Roger volunteered washing dishes one morning a week. Those harder to quantify included the volunteers with whom Roger washed dishes and the people who used the day centre.

What Figure Four does not convey is the way in which Roger's relationships had begun to change and develop immediately after the move. Early on Roger did keep

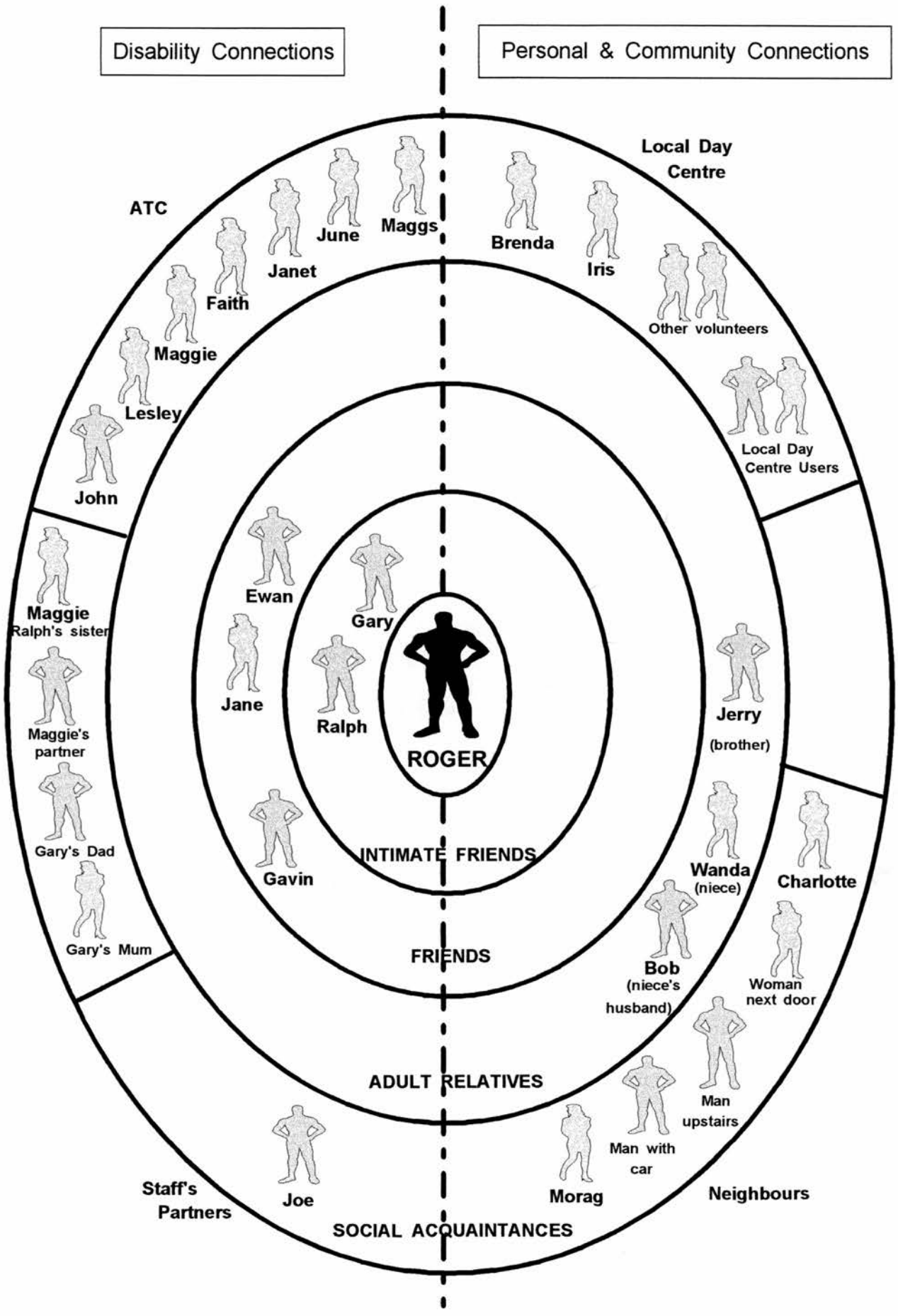


Figure Four: First Post-Move Network

in touch with Ewan and Jane, but staff questioned whether the former closeness and commitment in these friendships remained.

> I don't know how much he misses Jane...he doesn't ever volunteer to go down and visit...Roger certainly doesn't mention her very often.

Even less promising was Roger's friendship with Gavin, which did not appear to be maintained at all according to the first post-move diary. Meanwhile, staff were aware that Roger's relationship with Ralph was deteriorating in seeming favour of Gary. Staff recognised that Roger and Gary's friendship was the only one that was truly *developing* in this first post-move period.

> I think now Roger comes specifically to see Gary -to sit with him and play tapes together and this is a more positive thing.

In terms of family relationships, staff agreed that Roger's relationship with his brother Jerry had become a significant part of Roger's life. What had been limited contact prior to the move was greatly enhanced as a result of the move.

> Its a thing that's taken for granted now - that Jerry comes every Sunday...they're getting quite close now.

However, Roger's diary showed no contact in the first post-move period with his niece and her husband, who lived in another region of Scotland.

In terms of acquaintances, staff agreed his day centre work gave Roger access to great numbers of local people.

> He meets people when you're out shopping, he bumps into people everywhere who know him from the day centre.

Neighbours had also begun to show clear signs of welcoming Roger to the area.

> His neighbours are quite chatty. The neighbour with the dog cut Roger's grass for him one week.

The status of Roger's initial relationships: 2 1/2 years on

Figure Five demonstrates that the passage of 2 1/2 years brought a decline to every one of Roger's five closest friends. Some relationships declined sooner than others. Staff recognised Roger's relationship with Ralph continued to deteriorate as time passed.

> Sometimes Ralph will go to Roger's and he will ignore him. Ralph will come back saying Roger wasn't speaking to me.

Neither Ewan or Jane continued to have regular contact with Roger, and it seemed clear that this was due in part to Roger's lack of interest in pursuing the relationships. Roger's third diary shows one occasion where he was invited to Jane and Ewan's house for tea, while diary four shows no contact of any kind. In addition, the decline of Roger's relationship with Gavin was also Roger's choice.

> When they were together last week at Anne's party, Roger was obviously not interested. I haven't seen Roger do that for awhile - completely turn his head away to overtly ignore someone.

Finally, Roger's relationship with Gary, despite being considered the closest friendship Roger had throughout the post-move period, showed signs of deteriorating as rivalry set in. The reader will recall from Gary's portrait the comments made by staff about their disputes in the local neighbourhood over interactions with other community member.

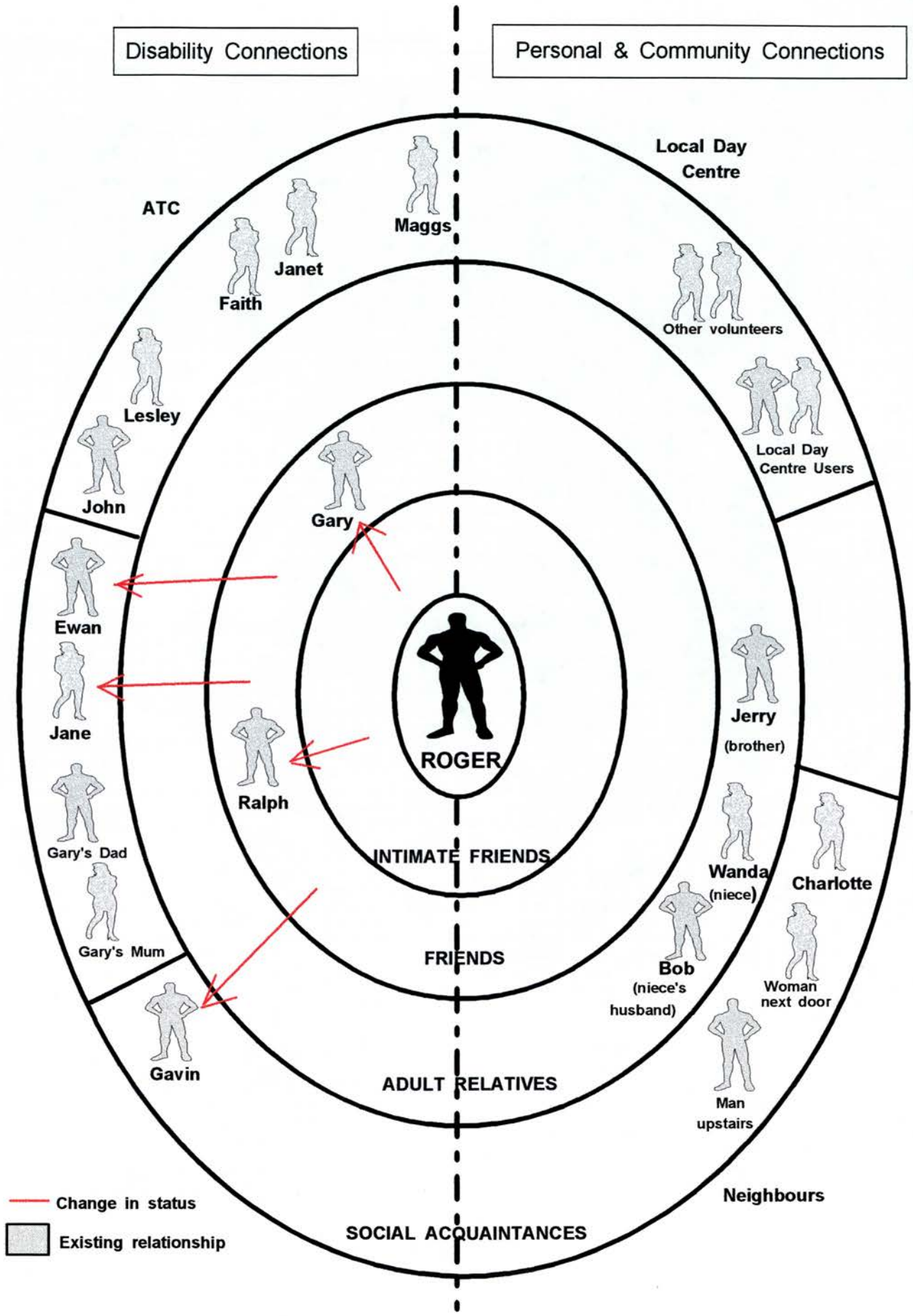


Figure Five: First Post-Move Network - 2 1/2 Years On

2 1/2 years on, the diagram also shows that none of the twenty-one relationships listed as Roger's acquaintances at the first post-move point, developed into anything more. Nine were lost, while those sustained revealed no apparent change in significance or depth. This was particularly noticeable in the relationships Roger had with his neighbours and the volunteers with whom he washed dishes weekly for 2 years.

> I don't think he has grown particularly in those (relationships). ...its not like he's invited anybody round.

In sharp contrast to Roger's friendships and acquaintances, his existing family relationships improved with the passage of time. Roger's relationship with his brother came to involve more regular contact, and greater significance for both of them.

> Now Roger will tell Jerry things that have happened before telling anyone else...Roger would be lost without Jerry coming to visit him now, and it would have to be something extra special for Roger to cancel.

In addition, Roger's relationships with his niece and her husband became more significant 2 1/2 years on.

> ...I know of at least twice, in addition to his occasional weekend visits to them, that they have just dropped in to see him, they maybe have been (up north) and they dropped in on the way home.

Although staff concluded that Roger would have liked to see Wanda and Bob more, evidence suggests the extent of his contact with them had increased since the move.

New developments in Roger's relationship network

Apart from family, the majority of existing relationships that remained in Roger's network 2 1/2 years on had declined. For a number of the close relationships, this appeared to be Roger's choice. To offset these developments, Figure Six shows only one new friendship appeared in Roger's fourth post-move network. This came in the form of an agency volunteer, matched with Roger quite late in the post-move period.

> Kitty would be a friend, but really you can't classify her as yet. They're just getting to know each other.

New relatives who had very limited contact (mostly by post) were a cousin and his wife. A number of new acquaintances joined Roger's network between the first post-move point and the last one. Six were people mentioned in the diaries who Roger saw mainly at the ATC. Other new community-based acquaintances came through Roger's involvement in a weekly keep-fit class for over 55's, a slimmers club, and volunteering at the local thrift shop. Four new neighbours were also added to Roger's network.

Figure Six fails to distinguish between *when* each of these new relationships became part of Roger's network and this was central to understanding the significance of these additions. I've already mentioned that Roger's volunteer was a late entry; yet despite this, staff quickly identified Kitty as a new friend. Roger's final diary showed Roger and Kitty visiting with each other in their homes. Roger's involvement in the thrift shop was also very new, and therefore he had only made acquaintances there. Contrasting this, Roger had been involved over a considerable

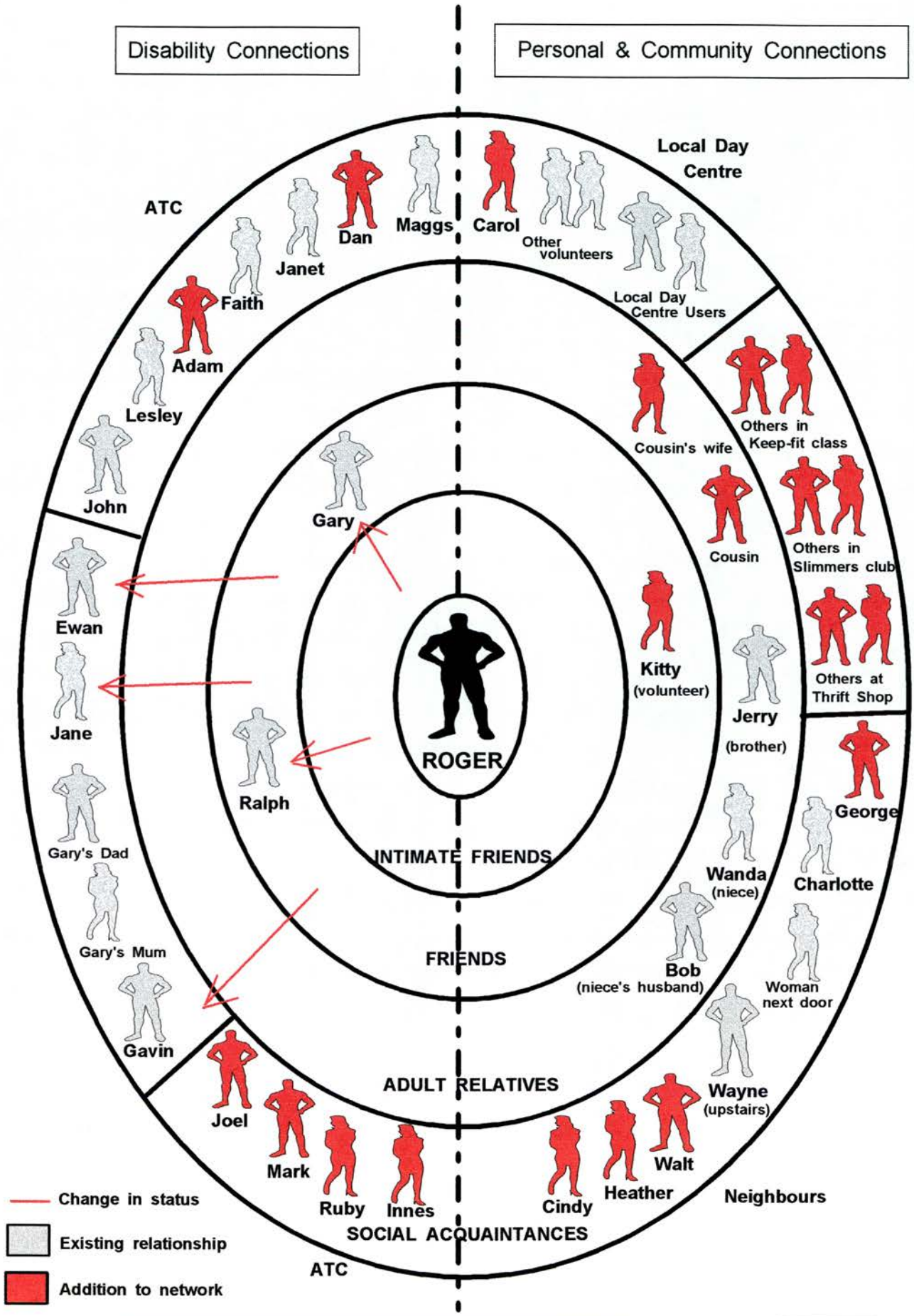


Figure Six: Final Post-Move Network - 2 1/2 Years After the Move

period in the keep-fit class and the slimmers club he attended. Despite this, the people he saw every week at these groups remained only acquaintances.

> There are a few people he says hello to, but I don't think there is anybody he's particularly fussed about.

In addition, Roger's familiarity with his immediate neighbours had been established soon after the move. They had an on-going relationship for over two years, yet the nature of those relationships remained unchanged.

> I don't think any of these relationships are that deep but he certainly has a lot of casual acquaintances.

On the family side, although Roger's visits with Wanda and Bob over a two year period gave him the chance to meet a number of other relatives who all came to visit them when Roger was staying there, they didn't stay in touch with Roger otherwise. None of Roger's extended family relationships had the day-to-day significance of Roger's relationship with his brother.

Finally, although there were new names from the ATC in Roger's diary, they were certainly not new additions to his life. These relationships, more than any other, illustrate the apparent 'going no-where' nature of all of Roger's acquaintances.

> Its always an issue at Christmas time - sending cards. He's known people for a long time but he just comes out with this list of names and you wonder how much any of these people actually mean to him, or whether he's just saying them because he knows them.

Reflecting upon Roger's relationship network: 2 1/2 years after the move

Looking back over the changes that took place within Roger's core relationships, it seems clear his relationships with other people with intellectual disabilities declined across the board, while his family relationships improved but expanded very little. Roger's brother was clearly his most intimate relationship, and evidence suggests they were friends as well as brothers.

In retrospect, Roger retained a greater percentage of social acquaintances than friends. Despite this, what is resoundingly obvious from the evidence presented is that not one of these long-standing acquaintances became more significant in Roger's relationship network. While there was particular potential for this with neighbours and fellow volunteers at the day centre, no friendships developed from those acquaintances identified at post-move one. In addition, his long-term involvement in integrated keep-fit and slimmers classes yielded similarly disappointing results.

Overall, the decline in Roger's initial relationship network was not offset by a comparable number of new relationships that would come to play a significant part in Roger's life. Yet Roger demonstrated a willingness to get involved with new people and a clear desire to get to know and interact with the many people he met in the local neighbourhood. Despite this, only his relationship with his brother seemed to flourish.

Community integration outcomes for Roger

Staff recognised at the first post-move point that Roger's closest relationships offered him little feelings of security. Although staff generally agreed that Roger's relationship with his brother, and new contact with other relatives who live farther afield, had added greatly to his life, they also recognised that he still had to depend largely on staff.

> His life very much revolves around staff, most of the other people involved in Roger's network are (agency tenants) as well, with the exception of his family. All the people on Roger's intimate friend list are people with intellectual disabilities. He would not turn to them for help because he'd know they wouldn't be able [to help]... they are all people in the same position as him.

The fact that Roger was more likely to turn to staff than when he lived in the hostel seemed only to exacerbate his dependence on staff. Roger's existing relationships ultimately provided little security compared with that provided by the staff team supporting him. Consequently, staff concluded that, at this first post-move point, Roger got his security from the staff team but also, to a limited extent, from his growing relationship with his brother.

In terms of belonging at the first post-move point, staff felt that the number of new social acquaintances in Roger's life was a very positive beginning, particularly the neighbours and local people who he'd met at the day centre. Staff agreed his feelings of belonging came from his community participation: in particular, his voluntary job, using the local shop, and his relationships with his neighbours.

2 1/2 years later, at the final post-move point, Roger's sources of security reflected the disappointing lack of new significant relationships in his network. Only the

balance, rather than the variety, of his sources of security had changed. It was clear Roger's brother provided him with a greater level of security. Otherwise, staff agreed Roger continued to get his feelings of security from staff.

> Really, when you think about it, so much of it still comes down to staff.

Although Wanda and Bob's relationship with Roger had become more significant, sheer distance still created a barrier to them providing any real feelings of security for Roger.

> There was not as much contact with Wanda and Bob as Roger would have liked...But I mean Kinkidro isn't exactly on the doorstep.

Contrasting this, staff clearly recognised that Roger's sources of belonging had grown significantly since the first post-move period. He had, of his own volition, made acquaintances of a significant number of neighbours and local community people.

> I think its through Roger chatting to folk, because when he's out on his walks...he will stop and chat away to them. He has no qualms about striking up a conversation, and its always appropriate conversation.

Staff recognised however, that Roger's belonging did not really extend to the local community, indicated by the comparatively larger number of people he knew from the neighbourhood, rather than from the town.

> Within Millside, he knows all the comings and goings ...I don't think there is any great connection to Trixdent itself. Roger's community is in this [neighbourhood].

One can only wonder why given the clearly positive response Roger received from his involvement in the neighbourhood and a number of community groups, he developed no new friendships (and consequently, no alternative sources of security) from these apparently hopeful beginnings.

Ralph

At the first post-move point, staff thought Ralph had struggled most with the move from the hostel. He showed much evidence of being unhappy in his current living situation, and was described as a person with a strong character, who had become frustrated and angry for a variety of reasons, many of which appeared to be related to his relationship network.

> Ralph's been ignored, marginalised, and let down a lot... sometimes what you see initially is rudeness - but its obviously something to do with the way his relationships have been.

Some staff felt Ralph was unhappy because he wanted to live with his sister.

> Who Ralph is actually living with [is] different than who he wants to be living with...He [thinks] he's just biding his time here...until he gets back [to living with his family].

Staff agreed that Ralph did not value other people with intellectual disabilities who were less able than him, preferring instead relationships with people without intellectual disabilities. He typically turned his efforts toward developing

relationships with staff; yet they described Ralph as having "an unfortunate manner."

> I don't think [staff] realised how difficult Ralph could be...
> Ralph likes being quite bossy and he can also be quite selfish.
> His network of relationships doesn't surprise me, but I think
> that's as much to do with the individual concerned as anything else.

Ralph's initial relationship network

Although Figure Seven demonstrates that staff felt Ralph had no intimate friends at the first post-move point, they agreed that Gary and Roger were the two closest relationships in Ralph's life, other than family. However, evidence suggests Ralph struggled with deciding whether he wanted a friendship with Gary or Roger.

> His feelings toward his friendships seem to change, they're
> best friends one day and then not friends anymore the
> next day.

Of the four additional people listed as friends, two had intellectual disabilities. According to staff, Ralph had always been keen to have a friendship with one of them - Laura - but the feeling had not been mutual.

> I don't think you could realistically call somebody a friend who
> you haven't seen for ages and she is making no effort to get in touch -
> is actually positively resisting the idea.

The two friends without intellectual disabilities were Fred, who used to work with Ralph, and Sheila, a neighbour who had been Ralph's befriender when he lived at the hostel. Ralph's diary showed he dropped in to visit Sheila and her husband regularly, since they lived close by.

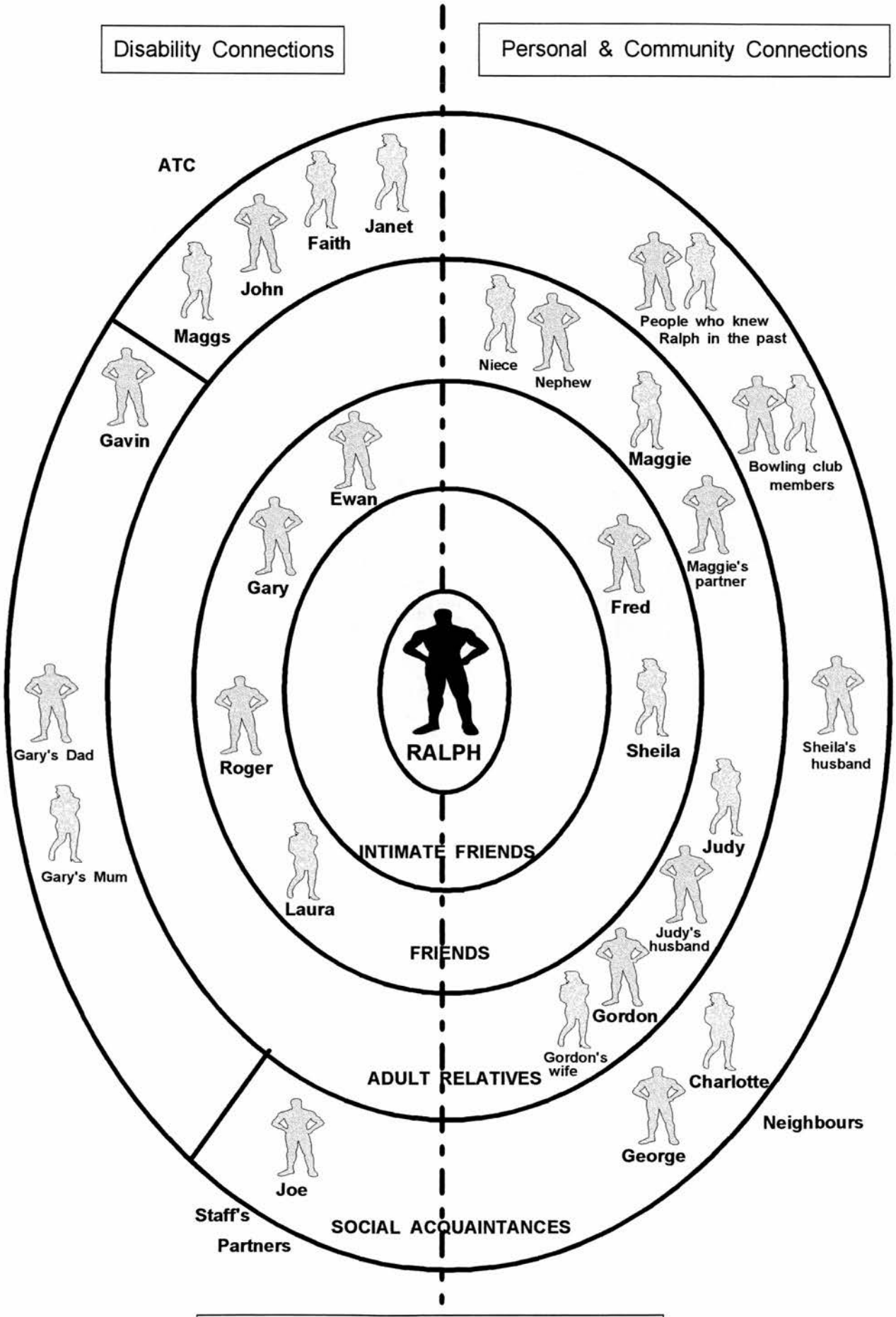


Figure Seven: First Post-Move Network

Ralph's family contact at the first post-move point involved two sisters and one brother, their partners, and a niece and nephew. Staff generally felt that Ralph's family had been supportive, although relatives tended to communicate with him on their own terms, and they hadn't always been receptive when he contacted them.

> When Ralph phones Maggie, she just says 'I'm busy' and cuts the conversation short....its very disappointing for him...When she phones here, she'll say maybe two words to Ralph and tell him to put staff on.

In terms of social acquaintances, Ralph moved back to the area where he grew up, and consequently was well known around the town.

> The town is a friendly place and people know Ralph by name and they speak to him in the street...at a social acquaintance level.

Ralph's first post-move diary frequently mentioned encountering people, for instance when he visited the local bowling club, who knew him when he grew up in Trixdent. Other acquaintances at the first post-move point included Gary's relatives, a staff member's partner, the couple that lived downstairs, and five people with intellectual disabilities, four of whom Ralph saw at the ATC.

Overall, staff recognised soon after the move that Ralph struggled, not only with the absence of intimate friendships, but also with the severe dissatisfaction he felt about the status of other relationships in his first post-move network.

The status of Ralph's initial relationships: 2 1/2 years on

The disappointing tone that characterised many of Ralph's relationships in the first post-move period offered a premonition of his network 2 1/2 years later. While Figure Eight shows that a number of relationships were lost, it does not convey the disturbing way in which this happened, and how many others deteriorated. Although staff were reluctant to move either Roger or Gary into the category of social acquaintance in Ralph's network, evidence suggests their friendships with Ralph declined. While Roger grew increasingly distant from Ralph soon after the move, Ralph's friendship with Gary also deteriorated considerably over the 2 1/2 years. The reader will recall the comments included in Gary's portrait. After 2 1/2 years, their relationship caused staff to believe Ralph and Gary should never have been flatmates.

> The relationship between Ralph and Gary is definitely much much worse...they both get on each other's nerves. Although Ralph can be quite dismissive and not really very nice, Gary is quick to give Ralph a row, even if he doesn't deserve it.

Compounding these developments, Figure Eight also shows that the four other people listed as friends in Ralph's first post-move network were losses 2 1/2 years on. Despite staff trying to encourage Ralph to keep contact with Ewan, their last visit together ended in shambles.

> Ewan was invited round for tea. Apparently, he got very upset about being here. He actually thumped staff. Ralph got very angry at this and said he didn't want Ewan to come back again...I really don't see why [this visit] was done, I mean Ralph doesn't have a relationship with Ewan - he never mentions him.

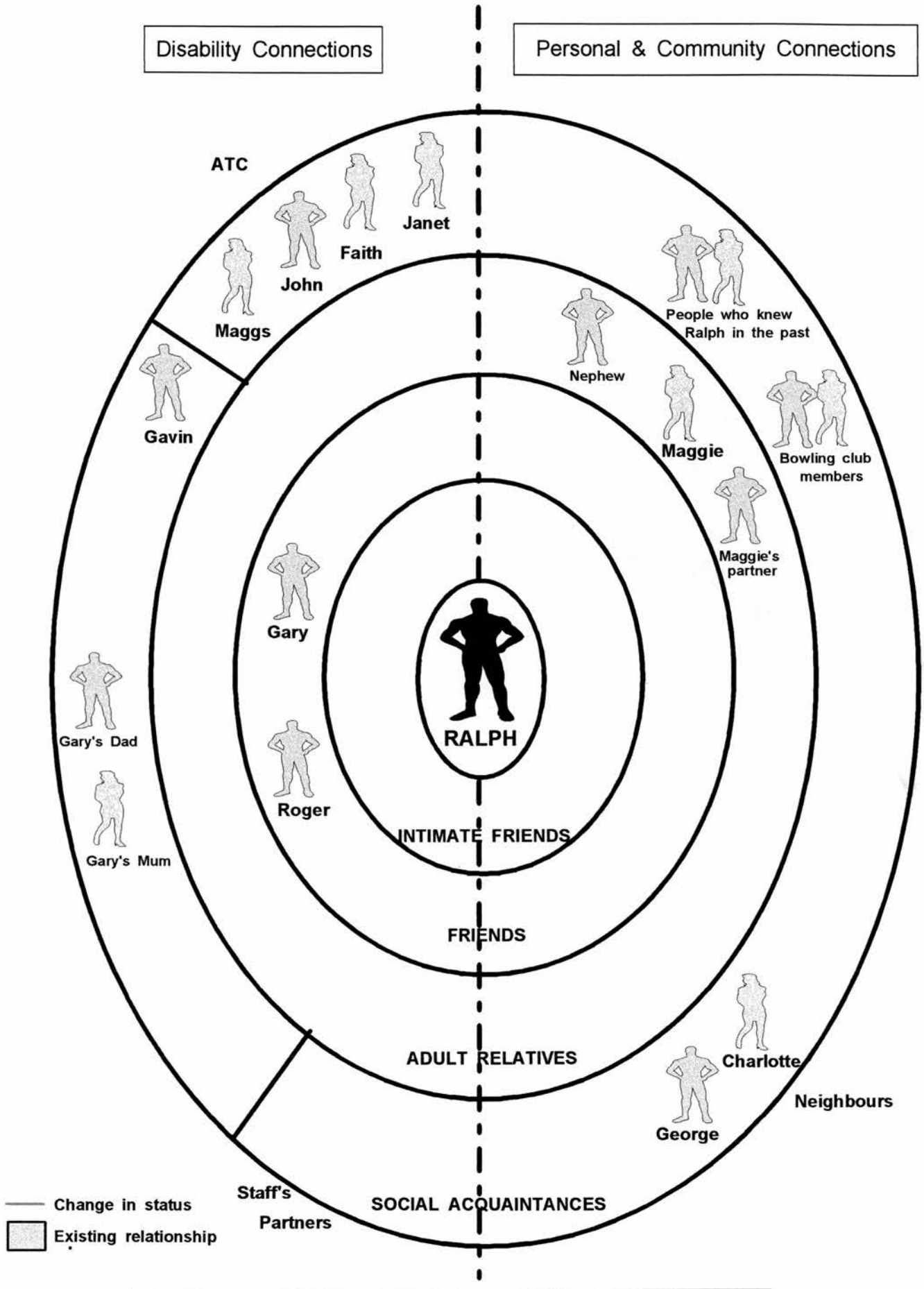


Figure Eight: First Post-Move Network - 2 1/2 Years On

Staff also agreed Ralph's relationship with Laura had become a total loss due largely to Laura's unwillingness to be involved with Ralph. Again, their last visit together seemed to seal the relationship's fate.

> I was on shift when Laura came to have tea with Ralph. There was next to no communication between them... it ended up she was going off to bingo at 6:30 and hadn't come to spend the evening with Ralph...we rushed to get tea prepared. All through tea she just kept asking me the time and was worried about missing her bingo. I had to make the conversation: they didn't speak to each other... After tea, she phoned a taxi straightaway, didn't say thank you, she just rushed off when the taxi arrived.

Ralph also lost contact with his former befriender (Sheila) and her husband. After two years, their relationship came to a sudden end when they moved house.

> There's been no contact since they left...They didn't leave Ralph an address or phone number. But they were never once to visit Ralph here, Ralph has always gone there...I honestly don't see them coming back into Ralph's life.

Finally, Fred came to work as part of Ralph's staff team, and listed himself as a professional when interviewed. He clearly saw the time he spent with Ralph as his work. Meanwhile, the passage of 2 1/2 years only cemented the reality of Ralph's disappointing relationships with his family. Ralph's relationship with his sister often seemed to prove more hurtful than comforting.

> If Ralph phones Maggie, I disappear out of the room. I don't want to be there because I know one of two things will happen. Either Ralph says 'hello Maggie' and she immediately asks to speak to staff, or the conversation lasts for a minute at the most and you'll hear Ralph say 'oh right Maggie, sorry Maggie, okay bye.' Its awful. And she will phone up and say she's coming to visit him and so there's Ralph, pacing about all day, waiting on her coming and then she comes and says 'I just dropped in with this' and that's it.

A significant sign that the family was increasingly cutting Ralph off came when his niece had a new baby. Ralph never managed to see the new baby due to the family cancelling a planned visit and never rearranging it. In addition, Ralph's brother died, and as a result Ralph no longer had contact with his wife, while Ralph's second sister, June, became very ill. The seriousness of this was kept from Ralph, yet visits between them stopped with no explanation given to Ralph.

Meanwhile, 2 1/2 years on, none of the acquaintances involved at the first post-move point had come to play a more significant part in Ralph's relationship network. In particular, the great number of people who were reacquainted with Ralph since he returned to Trixdent remained acquaintances, simply saying hello to Ralph in the street. In addition, Ralph's diaries also showed that his attendance at the local bowling club had stopped for over two years, and was just getting started again because a new member of staff had decided to take Gary and Ralph there.

Gary's relatives remained acquaintances of Ralph's whom he saw whenever they came to the flat to see Gary. The five people with intellectual disabilities continued to have limited contact with Ralph, and remained acquaintances. Although Ralph had invited one of these people over for dinner, this seemed more to please the project leader than to pursue a friendship.

> At first the project leader had been over and said that Jarrod doesn't get out much so Ralph said bring him over. Jarrod was here for about an hour...they got on but there wasn't much interaction between them.

Charlotte and George, Ralph's downstairs neighbours, remained friendly acquaintances. Ralph would occasionally help George in his garden and they had once helped Ralph back to the flat after he had a fall in the street. But in 2 1/2

years, they had never been in Ralph's flat socially, and he had been invited in for a cup of tea only once.

New developments in Ralph's relationship network

Near the end of the 2 1/2 year post-move period under consideration, Ralph was matched up with an agency volunteer. Figure Nine reveals this was the only new addition of friendship to Ralph's network. As far as family, there were no new additions. In contrast, Ralph experienced a significant injection of social acquaintances over the 2 1/2 year period.

Within the neighbourhood, Ralph would visit neighbours around the area during the summer months, and a new couple - Heather and Walt - were added. He also took it upon himself to begin helping out in the local shop. In addition, Ralph became involved in a number of activities that allowed him to meet a wide range of people. Early on, this included a number of disability-oriented activities. Ralph became the chair of the local People First and a member of the agency's management committee quite quickly after his move to Trixdent. As time passed, Ralph also became involved in a mainstream adult basic education class and he began volunteering one morning a week at the local thrift shop. Ralph also attended a woodworking group at a nearby group home.

Although Figure Nine reveals obvious gaps in Ralph's final network, the qualitative reality of these relationships holds the real key to understanding Ralph's experience.

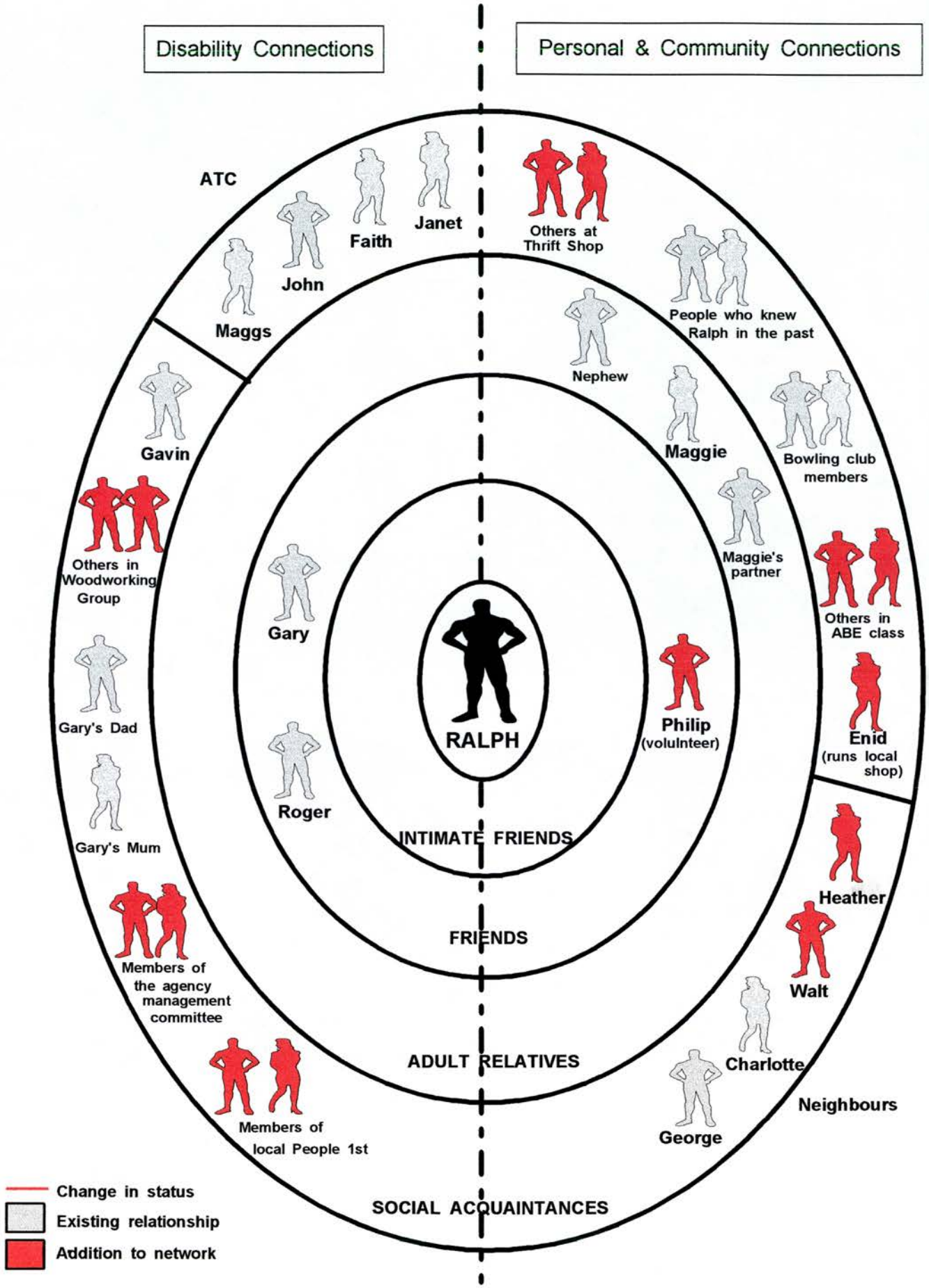


Figure Nine: Final Post-Move Network - 2 1/2 Years After the Move

For example, Ralph's volunteer (Philip) seemed to offer him a friendship which he valued, and which involved someone who valued him.

> Ralph sees Philip most weeks...He is very good and reliable, he phones regularly...I think they really have hit it off very well. Ralph has got just the right person ...it's the best thing that's happened to him.

The obvious increase in acquaintances in Ralph's network occurred over a period of time. Yet early developments in acquaintance relationships were no more likely to yield opportunities for friendships than later developments. For example, although Ralph dropped in to see Heather and Walt sometimes (especially in the summer), and they saw Ralph at neighbourhood events, their relationship went no further than this. A similar outcome evolved from his involvement in the local shop.

> Ralph has a wonderful relationship with Enid, the woman who runs the local shop. He goes round there and sweeps the floors and stacks the shelves...he spends a lot of time there.

Although Enid was also a neighbour, no contact with Ralph ever occurred when she was outwith her professional role as shop manager.

In terms of disability-oriented activities, these ultimately offered Ralph nothing in the way of relationship development. By participating in People First and the agency management committee, Ralph had the most contact with two people who were hired by the agency to support the development of self-advocacy. They maintained a long relationship with Ralph on this basis before they both left the agency just prior to the final post-move period. Most staff felt Ralph would not see them anymore and the final diary showed this to be the case. As well, in two years of service to the agency's management committee, staff reported Ralph never had

any informal contact with other committee members, indicating that they remained social acquaintances.

The story is much the same for Ralph's involvement in community activities. The ABE class Ralph attended for at least two years was a positive example of integrated involvement, yet staff agreed that two years on, the other members of the class were still nothing more than acquaintances. Ralph's involvement in the local thrift shop offered him very little chance to develop relationships since staff routinely changed every six weeks. Over time, it was clear that Ralph's pattern of involvement was, in and of itself, unlikely to lead to new friendships.

Ralph's relationship network - 2 1/2 years after the move

There are few portraits one could imagine that would appear more despairing than this one. Ralph's struggle to find satisfying relationships early on had ultimately left him with very few existing relationships positively maintained and none improved. Whereas there were clear incidents of Ralph rejecting people, there were more examples of him being rejected by others, particularly his family. The middle ground, 2 1/2 years on, revealed a very lonely man with few, if any, relationships he could truly rely on.

Although the move prompted contact with a variety of new people, living in Trixdent over the longer term brought no change to what were largely superficial relationships. The lack of change in Ralph's relationships with local community members who knew him in the past was significant in its totality: not one acquaintance from days gone by became more involved in Ralph's life with the

passage of time. Early on, neighbourhood contact, and the fact that Ralph could go visiting easily, seemed promising. Yet over time, his neighbourhood relationships remained largely one-sided with Ralph making all the effort to keep in touch. His befriender's move was a powerful sign of the tenuous nature of one-sided relationships enabled by sheer proximity.

When one attempts to explain why the variety of Ralph's activities yielded no new significant relationships, one obvious explanation arises.

> The history of Ralph's life has been things starting and then stopping. Things will get up and run for a month or two and then stop. Then maybe something else will come along.

Yet there is more to explaining the disappointing outcomes summarised above than a lack of continuity. There are clearly some activities in which Ralph had a long and consistent involvement. In retrospect, it seems that a more poignant display of opportunities failing to produce outcomes would be hard to find.

Community integration outcomes for Ralph

Soon after the move, staff generally agreed that the content of Ralph's network simply highlighted the extent to which he was dependent on staff for security.

> He doesn't really have any intimate friends...
> of the people he turns to, all of them are professionals....
> Ralph gets his security from staff around him, knowing that we are a steady presence in his life.

To a lesser extent, staff felt Ralph got his feelings of security from family, yet they recognised that Ralph's dissatisfaction with these relationships was likely to make him feel more insecure than secure.

Staff agreed that, initially, Ralph's feelings of belonging came from his contact with neighbours and being known locally. Yet although staff saw this as a very positive beginning, they also recognised that this needed to be strengthened.

> Ralph needs people he can go and visit, but not just going to visit, but doing things with them and people he can confide in.

Overall, in the first post-move period, although Ralph had made some superficial inroads into the community, he struggled to find his place with those who occupied the most significant roles in his network.

> Ralph finds it difficult to identify which 'group' he belongs to. His network is made up of staff, people with intellectual disabilities and family. I don't think he belongs to any of these groups.

2 1/2 years on, while Ralph's life was described by one staff member as "very busy with plenty of opportunity to meet new people, particularly people without intellectual disabilities," Ralph's friendships did not develop. Meanwhile, his family relationships deteriorated, causing Ralph to continue to rely on staff for his feelings of security.

> Ralph gets his feelings of security primarily from staff ...and knowing that there is somebody around who can come and offer help when he needs it. Ralph doesn't have an alternative source of security.

In terms of belonging, Ralph's continued presence in the local neighbourhood and

his involvement in a variety of activities sustained his belonging over the longer term.

> Ralph sees himself as a Trixdent boy...he's a belter,
> one of the boys - he really feels he belongs to Trixdent.

Overall however, even with a sense of belonging clearly established 2 1/2 years on, staff, and to a lesser extent his sister Maggie and his new volunteer, were the only people who had a significant role in Ralph's life. For the most part, Ralph continued to depend on professionals. Although he might have preferred to depend on family as he did before he moved to the hostel, this option was becoming increasingly less likely.

Ralph's final network certainly outlines the range of contacts he had made in the local community and his own neighbourhood. Yet again, one is left wondering why no meaningful relationships developed from this great variety of opportunities.

Chapter Conclusion

The portraits presented, while illustrating lifestyles that are developing, offer disappointing findings in the specific area of relationship development. Although the evidence suggests clearly that positive outcomes in relation to feelings of belonging did develop over the post-move period, as a *consequence* of community living, similar outcomes did not occur in terms of feelings of security. The absence of adequate relationships, that would offer alternatives to dependence on staff for feelings of security, seems evident in varying ways across all three of these portraits. Most vivid and consistent is the absence of genuine friendships.

The evidence clearly suggests both that little *growth* in the number of friendships resulted in the longer term, and that existing friendships were lost or began declining early in the post-move period. Although a certain amount of attrition in relationships could be expected for anyone who relocates and begins "a new life," what is particularly concerning about these three individuals' networks is the following:

1) that lost or declining friendships were often not the result of attrition due to loss of contact, but rather a "falling out" or rejection by one or both parties involved, which suggests these relationships were not genuine friendships;

and

2) that what began early in the post-move period as friendly and accepting acquaintance relationships with people without intellectual disabilities, developed into nothing more significant over a period of 2 1/2 years.

While these unfortunate realities are firmly established by the evidence, what resounds clearly through all three portraits is that, in the absence of significant friendships resulting from the two inter-related outcomes cited above, staff filled the void in terms of providing feelings of security. Although staff might arguably be considered a sustainable source of security in the long-term, this is a scenario that smacks of inadequacy when one considers the intentions behind key principles which have, and continue to underpin, the development of community care for people with intellectual disabilities: Social Role Valorisation; *An Ordinary Life;* and more recently, the Principles of Full Integration and Inclusion.

Throughout the 2 1/2 years considered, the people with intellectual disabilities at the centre of this study remained dependent on staff, and to a more limited extent on family, for their security. Only Roger experienced *increased* security developing in

a non-staff relationship (with his brother) over the post-move period. Meanwhile, Gary saw the nature of his family relationships remain unchanged, while Ralph saw his decline. Ultimately, the persistence of staff's significance in the lives of these three men continued throughout the post-move period. Despite the varied yet hopeful beginnings that each portrait illustrates, the lack of further development from this raises serious concerns. *Why* these hopeful beginnings failed to become more, and thus left the three men as dependent on staff for security as they were at the time of the move, is the subject of the next chapter.

CHAPTER EIGHT

"Determining the Impact of Staff"

Chapter Overview

In addressing the primary objective of this thesis, this chapter discusses the evidence collected which appears to offer some insight into explaining the disappointing relationship network and community integration outcomes documented in the previous chapter. In particular, evidence related to the role of staff is given significant attention. What ultimately results is a provisional explanatory framework that relates the attitudes and activities of staff to the specific relationship network and community integration outcomes which evolved for those they supported.

Introduction

It seems clear that the men's moves intensified their relationship with support staff, and this appeared to exacerbate staff's predominance in their lives. However, if one intentionally removes staff from each man's network as I did in the interviews conducted, they immediately recognised the inadequacy of these networks and the community integration they afforded.

> ...its only when you really look at something like this network - and you take the time to work it out and evaluate it - that it really makes you stop and think if there is a need for more.

This study was designed with the intention to determine *why* the relationship network and community integration outcomes that evolved, for the three men described in the previous chapter, did so; and in particular, *how* staff appear to have contributed to these outcomes. Given the unsatisfactory nature of each man's relationship network was both demonstrated by the evidence and acknowledged by staff, what remains to be explored is *what staff did* during the post-move period considered, and how this may have been related to these disappointing network outcomes.

Although I explained in Chapter Five why attempting to explain the disappointing outcomes by generating strict causal theory would not be possible, this chapter is designed to explore the plausibility of one explanation (the impact of staff) for the outcomes observed. As a starting point, ten themes are introduced which collectively characterise the nature of staff attitudes and activities. The identified attitudes and activities are discussed and evaluated in light of their relevance to, and impact upon, relationship network development. In addition, the activities of the sponsoring agency are considered from a similar perspective, to build on the reader's understanding of the agency's role in influencing the attitudes and activities of staff which was initially addressed in Chapter Six. Finally, the attitudes and actions of community members are considered in light of how they may have also contributed to the attitudes and activities of staff. In drawing conclusions, a provisional explanatory framework is presented and discussed which demonstrates how the various themes introduced in the chapter appeared to interact and ultimately contribute to the relationship network outcomes observed.

A. THE NATURE OF STAFF ATTITUDES & ACTIVITIES

1. A tendency toward 'rose-coloured glasses'

Atkinson (1987) found that people with intellectual disabilities often identified people as friends who clearly did not have that kind of relationship with them, but were typically acquaintances or professionals. This study confirmed this finding.

> The men seem to define friend as someone they recognise or know. Because they know them, they say that person is a friend.

Yet it seemed staff were also likely to classify the tenants' relationships more favourably than the evidence suggested was the case. This 'rose-coloured glasses' approach was particularly evident when considering the men's relationships with neighbours.

Take for example, Charlotte, who was consistently listed as a friend in each man's network. One staff member characterised her relationship with the men as "an on-going everyday thing", despite the fact that her contact with the men suggested she was no more than a friend*ly* acquaintance. In Gary's first post-move diary, the extent of their contact over a six week period consisted of one episode in which Gary had a passing conversation with Charlotte in the garden. Over time, staff's own evidence suggested friendship remained an inappropriate characterisation.

> Gary's got to realise, just because people are being friendly to him (doesn't mean they are his best mates)...like today, he grabbed Charlotte from outside and dragged her up to look at his radio. He is known to her but I don't think in that sort of way.

Similar 'rose-coloured' characterisations of the men's relationships with other neighbours arose.

> Heather and Walt have definitely become friends. They haven't had much contact recently [but] Gary is very pleased to see them.

With all of these neighbours, there was a sharp drop in contact over the winter months that, while typical of neighbours, would hardly be typical of friends. As well, although the men visited Heather and Walt, they never visited the men, or had any form of planned contact. Although these relationships represented positive beginnings, their classification by staff as friendships was not an accurate reflection of the evidence.

The 'rose-coloured glasses' tendency also arose with the men's relatives and volunteers. For example, staff often suggested Roger's brother and Ralph's volunteer were friends of Gary's, despite the absence of any contact other than when they came to visit Roger and Ralph respectively. Similar patterns of contact existed in Roger and Ralph's relationship with Gary's parents, although a number of staff suggested they were friends. Finally, some staff also wanted to move community professionals into the category of friend or social acquaintance when evidence suggested they never had more than professional contact with the men.

Overall, staff seemed reluctant to recognise the friendly aspect of what the hard evidence demonstrated were either acquaintances or professional relationships. When staff were challenged to think about the quality of the relationship networks of those they support, one response was to adopt the 'rose-coloured glasses' position and simply conclude things were better than they really were. Consequently, there was justification for less proactivity around relationship network development. The sections that follow document the evidence that supports this conclusion.

2. An emphasis on maintenance rather than development

In discussing with staff their efforts in the area of relationship network development, a distinction was made between *maintaining* existing relationships and *developing* new relationships. This ultimately proved critical in understanding the impact of their efforts overall. Early on, some staff recognised that their efforts were mainly tied to maintaining existing relationships, and evidence demonstrates they seemed particularly concerned with helping the men maintain relationships with other intellectually disabled people and relatives.

> [We've] not been actively involved [in helping people develop new relationships]. I mean not actually persuading people to talk to somebody that they might not have otherwise...[but with maintaining relationships] we may have actually prodded people to get in touch..

Yet even staff's efforts in the area of maintenance were often questionable. For example, staff did not always seem aware of the various people who existed in the three men's networks, and they didn't think to involve them at key times. This was particularly true at Christmas when, in making plans for a party, staff didn't think to invite specific friends or relatives of each of the tenants. Rather, they thought only of other group homes in the project.

> Last year, we had the Christmas night out with Clinking Road.
> This year, I wonder what the Dodden Gardens people are doing...
>
> There's no social interaction if we go to a dinner dance as a private group.
>
> So to make it social, our group and Dodden Gardens could meet as one.

As well, when Ralph had a bank holiday weekend at home on his own, staff didn't think of people he might want to see, only places he could go.

> By Monday, Ralph will be chewing the carpets with boredom. He hates bank holidays.
>
> Well, there's North Bidwick and other places he'd enjoy going.
>
> Yes, there's the leisure centre and places like that...they don't close.

In addition, if maintaining relationships created 'inconvenience' for staff, they sometimes opted not to help the men do this. For example, during holiday time, when making plans for Roger, there was no suggestion of visiting relatives because staff were not keen to make the trip.

> I'm surprised Roger didn't say he wanted to go and see his cousin, not that I wanted to go back.

In another example, staff intervened in Roger's visits to Gary at night, because it interfered with their schedule.

> Roger comes round at 9:30. Staff aren't wanting to come out that late to do his meds.
>
> We have to tell him to leave...
>
> When supper-time starts, you want him to go so you can get on with it.
>
> Maybe you should talk to Gary and Ralph - tell them we're finding it disruptive to the whole routine. Tell Roger when two staff are on, staff will come over and stay with him.
>
> I don't like having to walk in the dark.
>
> Maybe Roger should be banned from [Ralph and Gary's flat] for a week. This would encourage Gary to go over there for a change.

In the end, despite staff agreeing that they put most of their efforts into helping the men maintain rather than develop relationships, it seems even these efforts were not without their serious shortcomings. Sometimes, obvious opportunities were simply not pursued.

> I went and joined in with Roger at his keep-fit class.
>
> Did you look in on Jerry afterwards. His house is so close, just round the corner...
>
> Roger pointed it out to me but no [we didn't stop].

In terms of developing new relationships, one staff member summarised the reality very well, saying:

> We really only [help tenants develop new relationships] in a haphazard way when we are working with them.

No where was this more obvious than in the range of activities the three men were assisted to become involved in.

3. Planning and supporting opportunities to participate without consideration for relationship potential

Given the evidence introduced in Chapter Six, highlighting the importance staff placed on *opportunities* in the process of developing new relationships, it seems staff did pursue and arrange a variety of opportunities for Gary, Roger and Ralph to participate. However, in terms of relationship development, these opportunities did not result in any new friendships or sources of security. One reason seemed to be that staff rarely pursued these activities with a relationship development agenda.

One vivid example of this involved Roger, who was assisted to join both an over fifty-five's keep-fit class and a slimmers club. Although integrated and community-based, staff discussions revealed these opportunities were pursued mainly because Roger needed to watch his weight. No one seemed to consider his needs around relationships and these remained unaddressed in the support that staff provided to Roger. For example, staff intended not to accompany Roger to the keep-fit class, and until the instructor insisted someone be there to help him follow instructions, staff didn't see the need for their involvement. Even when there, they intentionally avoided involvement where they might have been able to facilitate new relationships, assuming instead that they would be interfering.

> Roger always talks to the instructor after every class.
> I just stayed back...its none of my business.

Holidays were another 'activity' which staff put a tremendous amount of effort into organising and supporting. Yet again, building relationships did not seem to figure in their work.

> Ralph went on holiday with Gerald although how much interaction they had I don't know. I think Ralph was invited because they had a spare place and it was the kind of holiday that would appeal to him more than that he was particularly great mates with Gerald.

Twice however, staff arranged holidays for Gary and Ralph which involved staying with staff's friends. Although staff utilised their own relationship networks to connect the tenants to people outside the world of disability, these holidays involved meeting friends who lived in distant places. There was no evidence of staff introducing the tenants to friends who lived locally, where the potential for on-going contact and perhaps friendship would be much greater. Where this happened on holidays, it seemed it was done to avoid the cost of overnight accommodation.

In general, holidays were organised around the needs and preferences of staff, who were often thinking more about their own circumstances than the issue of relationship development.

> I would prefer to [do this holiday with Gary] soon because when it gets to summer, I won't be as keen to be away from home overnight.

Staff sometimes reacted to logistical problems of participation in the local community by suggesting that tenants discontinue involvement, meaning that existing opportunities for relationship development would be lost.

> The library said they might have to charge Gary [for the damage he's done to the books he borrowed].
>
> Maybe he should buy some books instead of using the library.

Even more worrying was the pattern of Ralph's involvement in woodworking. When the hospital unit Ralph attended was closed, Ralph began attending a woodworking group at another local group home. Although this interrupted what had been a regular weekly visit to a local cafe where he knew the owners quite well, the positive relationships he developed with the other men in the woodworking group seemed to offset this loss. Yet the occupational therapist then suggested that Ralph shouldn't *have to* go to the other group home for woodworking, and proposed instead to bring the woodworking supplies to Ralph's flat so he could do this work at home each week. Ralph went from an integrated social opportunity, to a segregated social opportunity, to an isolated opportunity to work with wood. What is most disturbing of course, is that the involved professional thought her suggestion was the *ideal* option. Clearly, the importance of developing relationships was not part of her thought processes.

Finally, where staff tried to find specific opportunities to participate by focusing on the men's interests, they were sometimes amazingly disability-minded in their search for alternatives.

> I don't think any of the pubs have dominoes on a regular basis. If Ralph likes doing something with his hands, there's the blind and partially sighted club...with sighted volunteers.

There was often a particular sense of urgency around segregated opportunities which arose. In particular, the chance of Gary getting a place in the 'Thursday club' was said to be "an opportunity that [staff] shouldn't let pass by", while applications for 'Riding for the disabled' were urgently handled in a staff meeting. This was likely to be due to the general lack of alternatives in which the men could participate without staff support. This need for staff presence and support proved, in and of itself, to be a critical theme.

4. A preference for non-involvement

Where Jahoda (*et al.* 1990) found that people lacked opportunities to make contact with new people, and this explained why their relationship networks changed little, this scenario was clearly not the case for Gary, Roger and Ralph. Consequently, when looking for explanations as to why positive relationship development did not occur, despite a range of opportunities to make contact with new people, it seems critical to identify 'common denominators' that existed which might offer an explanation. Indeed, one common denominator in this study was often *the absence* of staff presence *and* support.

Although inadequate staffing levels provided an obvious explanation for why staff would seek out opportunities that did not involve the need for staff support, this seemed to be only part of the reason why these activities were pursued. It also appeared that staff sought these opportunities because they held the view that allowing the men to 'go it alone' was a positive strategy. This attitude mitigated against staff recognising the potential benefits of their involvement - particularly the benefits around facilitating relationship development. Consequently, even when staff *were* present, their reports of their involvement demonstrated very clearly that they were not providing support to facilitate relationship development. For example, recall one staff member's attitude about Roger's interaction with his keep-fit instructor being 'none of her business'. This was also the position adopted in accompanying people into town.

> [The people who greet Roger in the street] very rarely speak to me, because they don't know us, they know Roger.

A similar line was also taken in relation to finding out about existing relationships, and often staff didn't see the shortcomings of such an approach unless it was pointed out to them.

Staff: When it was Gary's birthday, we went out to a pub in North Bidwick. He knows a lot of people there that we know nothing about who have been in his network for a very long time. Why shouldn't they have a life that [staff] don't know about?

Researcher: But isn't helping tenants maintain and develop existing relationships part of your job?

Staff: Yes, but I feel Gary's parents take care of that. However, if they dropped dead tomorrow, we'd be in the dark. I hadn't thought about it like that before...as far along the line as that.

Predictably, where staff weren't physically present, there was little question as to why they were not in a position to facilitate relationship development.

> Roger might be doing brilliant...I just don't know. It occurred to me that it would be quite good to have a session [at the day centre] with Roger...[but] its very much Roger's thing so we don't want to interfere... we want him to establish his own network down there that's nothing to do with us, but it would be quite useful to [know] how its going so that we could help him make it better.

Sometimes, it seemed that staff would actually entertain the idea that an on-going opportunity to participate should end, if staff had to become involved. This was the case when Ralph's gardening was in danger of stopping because the instructor no longer had time to support Ralph himself.

> Ralph really gets a lot out of it, especially because its people not associated with us [staff]. If one of us goes, it would ruin it.
>
> Yes, it would be backward step. His independence would be lost.

In the end, staff's view that they should not be involved seemed an unproductive emphasis on independence that resulted in little or no relationship development. While staff acknowledged that "the hard part [for the men] is getting to know people once [they] are [in a social situation]", they opted to avoid becoming involved, rather than recognising their ability to facilitate this 'hard part' by being present.

Although one should not belittle the significant barriers to staff involvement which resulted from inadequate staffing levels, the attitudes of staff suggested that even with adequate staffing, they would have tended toward remaining uninvolved. Inadequate staffing in particular caused staff to seek out segregated activities, often to free staff from responsibility.

> Staff think...'great that's Roger out of the picture' because he's off doing that [without us] so its one less thing for us to think about.

Although one staff member said "we do more than just take [the men places], we encourage them to participate as we would," another staff member described their

efforts in the following way:

> Initially, we [staff] help to set up things and then they roll along by themselves. To a large extent, we have gradually withdrawn from these activities. In terms of [the men's relationships with neighbours], we haven't put a great deal into that at all. With Roger particularly, we wouldn't know what was going on.

In retrospect, it seems this lack of staff presence and support, which existed in most of the opportunities the men had to participate socially, could be the common denominator that explains why such varied activities consistently led to little relationship network development. When prompted, staff certainly recognised that they could do little to assist the men in pursuing relationships if they were not somehow involved.

> I think I could quite easily see myself suggesting to Roger to buy one of the women he washes dishes with a birthday card if he came home and said it was her birthday. Or even sending one of them a postcard when he went on holiday so saying to Roger to ask them for an address...But [I'd] have to suss out how the relationship was anyway.

Inadequate staffing, however, did seem to provoke some perversely positive outcomes in that it sometimes forced staff into a position where they had to facilitate relationships in some way to ensure the men had the support they needed.

5. Seeking support from the community members only in times of crisis

Not only did staff seem to take the view that they themselves should avoid being directly involved in supporting the men with their activities, they also demonstrated a tendency to seek support from community members for the men only in times of crisis. Taken together, these two positions conjure up an image of isolated participation, where no one is identified or expected to facilitate involvement and

the men are simply *dumped* at the correct venue.[1] More often than not, particularly with integrated activities, the evidence suggests this was what happened. Although seeking the support and involvement of community members could have provided the basis for enhancing existing relationships, staff appeared reluctant to 'impose' on people by asking them to welcome and take an interest in the men while sharing activities together. One staff member commented: "we just don't want anybody to feel obliged."

Not surprisingly then, where evidence shows staff did look to others to offer support, this was only as a last resort.

> Roger was not up in time for his work. I had to phone and tell them he would be late. Then, I had to ask the taxi driver to help him cross the road where he drops him off [because I couldn't go with him]. The taxi driver said he'd gladly do it...said he wouldn't let him cross the road on his own anyway.

The absence of staff support sometimes forced staff to test out the nature of the men's relationships with their social acquaintances, and this (like the scenario above) usually had positive results.

> I remember when the local day centre volunteers were having a day out. They were going on a bus tour. They wanted Roger to come and then a few days before they got in touch and said they would like Roger to be accompanied. We just didn't have the staff. We went back to them and said Roger didn't want the staff to go with him, but we assured them we couldn't foresee any problems. And they took it on board, they said he should come and they would look after him. So that was an occasion when we discharged our duties...but if we hadn't...Roger wouldn't have gone.

Staff's failure to seek the support of others involved in the men's life also seemed to apply to relatives. With Roger's brother Jerry, seeking support came only when a

crisis arose, although a crisis related more to staff unwillingness than unavailability.

> There's a concert in Ireland and it involves a two night coach trip. Roger wants to take Jerry as well.
>
> The only thing that worries me is coping with Roger and Jerry as well.
>
> It would be hard going [for you].
>
> Could we consider two members of staff going?
>
> No, why can't Jerry cope with Roger on his own? Phone him and ask him how he feels about it, then [staff] wouldn't have to go.

While there was no mention of encouraging Jerry and Roger to go out together without support during their weekly visits, when this scenario arose, the team decided to make the suggestion. In these and other examples, what is most significant is the fact that staff apprehension and reluctance was ultimately met with community willingness. Yet, this failed to change staff's tendency to avoid pursuing support for the men when there wasn't a crisis situation. In both Roger's keep-fit class and Ralph's gardening, while staff acknowledged the men's need for support, they never considered the possibility that others involved in these groups might be able to offer the necessary support. This, combined with staff's unwillingness to become actively involved themselves, made these opportunities almost predestined to yield no genuine opportunities for relationship development.

6. A tendency to focus on the needs and preferences of staff

Although some examples have already been mentioned, where staff's preferences dictated the nature of their activities and initiatives, the sheer extent to which this prevailed justified identifying it as a unique theme. In terms of facilitating

opportunities for the men, what was on offer often depended on what staff liked doing.

> I think F. loves going to the pictures so they get to go to the pictures more often now.

Whether or not these opportunities offered the potential for relationship development did not seem to be an issue. In retrospect however, some staff recognised what Walker (1995) found: that some activities and places do not lend themselves to developing new relationships.

> Its like you're on your own in the pictures...its dark and quiet and you're just watching...you don't share the experience.

Yet setting aside a debate over the *quality* of opportunities staff *did* provide, sometimes they simply did not provide certain opportunities because staff preferences mitigated against this. In some cases, not only were the men directed toward activities which suited staff, but staff also resisted pursuing things the men clearly enjoyed.

> The Anderson Brothers are at the local hotel. We could go for a meal and the show.
>
> No, I'd like to pass on the Anderson Brothers, although the men would enjoy it.
>
> We can leave them to it and go to the bar.
>
> [I heard L. say she] hopes she won't have to go.

Staff also resisted encouraging the men to pursue particular opportunities that, although they agreed would be very likely to yield the potential for new relationships, went against staff's personal preferences. For example, although staff felt the local church would be a likely place to develop relationships, the fact that

none of the men attended seemed to reflect more the choices of staff rather than the men.

> You would think a Christian community would be welcoming of people from all walks of life because of their philosophy generally... but the problem is that the staff have to want to go as well, and I think this staff team is pretty agnostic.

What was however, most disturbing is that some staff may have actually resisted pursuing opportunities of any kind purely because they did not wish to leave the home situation.

> They are bored sometimes in the house so you just get up and put the kettle on...there's nothing wrong with being in the house, not a darn thing.

The men's diaries revealed that this staff member's seeming contentment with 'staying home' resulted in her rarely going out at night or at weekends with men other than to standing engagements where regular attendance was expected. This seemed more to do with this individual staff member's motivation than anything else. Another staff member raised the issue of staff's motivation as a seasonal one.

> [Staffing levels] have improved a great deal over the last few weeks because no one is on holiday. Its just unfortunate that this happens in winter, when the inclination to go anywhere or do anything is not as strong.

In terms of helping the men maintain existing relationships, staff's needs often determined when they initiated contact with relatives. This was particularly evident in planning for the Christmas holidays, where contact was prompted by staff concerns about whether they would have to work.

> Maggie normally takes Ralph for Christmas. A discrete phonecall would do no harm. Tell her we're doing the rotas, and need to order handicabs soon, then we'll know [if we have to work] for sure.

Otherwise, evidence suggests staff did not initiate regular contact with relatives in an effort to facilitate the maintenance or development of these relationships for tenants. Contact that did occur was typically based on solidifying arrangements initiated by the relatives. In the case of Ralph's relationship with his sister Maggie, evidence clearly demonstrated that where contact was not initiated by Maggie, staff had little contact with her over considerable periods of time.

Finally, staff also expressed a reluctance to work in ways that may have facilitated greater social opportunities for tenants. For example, staff rejected the idea of rotating as a 'floater' for evenings and weekends, while the project leader took the view that no staff should be expected to work split-shifts.

7. A tendency to disregard the importance of individuality in extending the relationship networks of tenants

Despite the fact that one staff member commented early on that Gary, Roger and Ralph had lifestyles 'as different as any other three people', the evidence suggests this was clearly not the case. The men's lack of separate lifestyles had critical implications for the potential of relationship development, particularly with regard to density issues. Bulmer (1987) identifies a number of drawbacks in terms of social support that result from having overly dense networks.

> They are likely to be restrictive...limiting opportunities for innovation and new contacts. Wilcox (1981) quoted by Bulmer, noted that people facing a change in lifestyle or role were able to adjust more successfully if their existing social networks were relatively loose-knit, rather than close-knit.

Given that the men's existing relationship networks were inordinately dense, due to the nature of their lifestyles prior to the move, opportunities to develop new

relationships that would curb this density became particularly important. But I am speaking here not only of the density *within* each man's network, but also of the density *between* the three men's networks. Unfortunately, evidence suggests staff were often unaware of how the successful development of supportive relationship networks was strongly linked to the facilitation of individualised lifestyles. They were often more concerned with achieving equity between the men and quantity of opportunity, than with more qualitative considerations.

> These social events tend to be things that they would all like so it would be excluding another person by not taking them along.

Generally, if new activities went well for one of the men, staff reacted by wanting to include the others.

> Ralph thought the Thursday club was great. Did anybody find out if Gary can go too?

Sometimes, the arrangement of opportunities was assumed, from the outset, to be for more than one of the men.

> Monday evening gentle keep-fit class is starting. Gary says he wants to go. We'll start off with Gary and then see about Roger joining.

The project leader seemed particularly keen to include large numbers of tenants in certain opportunities.

> Roger is going to this concert. He has a video of the guy who is performing. [The project leader] said Ralph and Gary need to be asked, and also the Hidlington group.

Staff routinely made efforts to involve at least two if not all three men in opportunities they found. For example, staff applied for all three men to do 'Riding for the Disabled', while both Gary and Ralph were 'assessed' for adult basic education. In addition, after Ralph had been working at the thrift shop for some

time, Roger also started volunteering there. Beyond these routine weekly activities, it was usually imperative that all three men were involved in special events.

> The People First conference is coming up. Ralph is on the committee so he will want to go. The project leader said we should ask the other men if they want to go...she said we can just use one application for all of them.

In retrospect, it seems clear that the lack of individualised lifestyles for the men was at least partly due to staff's lack of awareness of the importance of this in facilitating relationship networks. The homogeneity, both within and between the men's lifestyles, undermined the potential for diversity in their relationships. This consequently limited the extent to which each man could depend on those in his network for social support. Those people who appeared in all three of the men's networks were likely to face the same tension staff often spoke of in relation to being 'fair' in their dealings with the men.

> Each person here appears to like time spent with staff which is away from the other tenants. Quite often you've got to balance it so you don't appear to spend any more time with one person or another.

Volunteers in particular it seemed would find it difficult to feel comfortable about becoming strongly involved or committed to one person.

> If you volunteer, you are having to meet all three men and people are obviously not volunteering their whole life yet because all three men are here, people feel like no matter what time they give, its never enough.

On reflection it seems that where an allegiance to fairness and quantity of opportunity overruled any concern for density issues, the men's lifestyles remained decidedly similar. Consequently, the overlap in their relationship networks diminished little over time, thereby severely limiting the variety of sources of support to which each man had exclusive access.

8. Emphasising the promotion of home-life and functional independence agendas

The emphasis upon staff's concern for relationship network development that has underpinned the previous seven sections will be slightly shifted now to reflect more comprehensively the evidence collected. In considering the overall body of data, it seems the evidence presented thus far, which specifically demonstrates staff's lack of attention to and concern for relationship network issues, was not simply the result of ignorance on the part of staff. Rather, one can see that staff were largely channelling their attention to other areas, and that this was the primary reason why their concern for relationship development appeared to be so significantly lacking.

Despite a recognition of the agency's commitment to all five of O'Brien's accomplishments, evidence suggests staff were preoccupied with promoting the development of home-based skills and functional living patterns.

> I think [our priorities] should lie with people being able to get out and about and meet people to form relationships; but then I don't really know on that one. I think that's maybe a case of running before you can walk...I think independence should come first, we definitely concentrate on that most.

The pattern of initiatives staff undertook generally demonstrated that *'life begins at home'*, although not in this case, because the people one lives with are most important, but rather because staff viewed the things that go on at home as the priority. Evidence from staff meetings revealed that they frequently undertook a number of initiatives related to the home and the need to promote functional skills. Cleaning proved to be a significant agenda item, which ultimately resulted in more

staff hours being committed to this over time.

> Its a question of how we set about [spring cleaning].
>
> You need weekly and monthly task lists. Like windows are done once a month. Break it down into weekly, monthly and three-monthly task lists. The only way to make it fair is to make up a cleaning rota.

In a similar example, existing cleaning arrangements became significantly more frequent at the request of particular staff members.

> The cleaning of the bathroom seems to have slipped to once a week...
>
> Should we allocate time for staff to do it on their shifts?
>
> I think it should be everyday or every other day.

Evidence from staff meetings also suggested there was a significant emphasis on behaviour programmes and task analysis. With regard to issues of a functional nature, like bathing, dressing, and cooking, the project leader often suggested a task analysis or behaviour programme be written out by staff. While sometimes this was done because a tenant was experiencing difficulties in a particular area, staff also adopted additional initiatives that focused on improving the men's home-based, functional skills.

> We could get a meal each man likes and help them make it one night a week until they can make it on their own.
>
> Yes, but its better to pick nights to cook with the men when two staff are on so we have the time.

Each time an undertaking such as this was pursued, both staff and tenant's time were allocated to home-based activities. In the above example, the potential for social opportunities that would arise from having two staff on was disregarded in favour of working on cooking skills.

Sometimes the home-based focus was not motivated by concern for the men's development, but rather by expectations that staff had of each other in relation to their duties.

> We've got to do all these domestic things like [prepare meals], wash the dishes, do some ironing... You don't walk out and leave a sink of dirty dishes - the pressure is always there to get these jobs done before the end of your shift so that the person coming on shift is not left with it.

It seems the standards staff imposed on each other were often likely to translate into barriers to working on relationship development. Indeed, staff's view that they lacked the time to pursue opportunities for relationship development seemed more to do with their expectations of each other resulting in unavailability rather than the sheer absence of bodies at the time these opportunities arose.

Expectations from the agency also reinforced the home-base, functional emphasis. In particular, the project leader's expectations clearly centred around this.

Researcher: What are the things that get the project leader upset if they are left unattended?

Staff: Task analysis - that's the big thing on the agenda for all the men, staff all have to do some of them.

Over time, it also became clear that staff were increasingly expected to do the work of agency managers like doing their own rotas, fund-raising and writing guidelines and procedures for the project. Interestingly, the agency made no reference to relationships or community integration when identifying the list of subjects for which staff had to write out guidelines and procedures. Perhaps there is no clearer evidence of priority agendas than those things for which the agency deemed it necessary to develop written guidelines to ensure its own accountability. To some extent such agendas were also imposed externally, particularly through registration

procedures to which the agency subscribed. Evidence from staff meeting observation clearly demonstrated the impact registration issues had on determining staff's priorities. For example, staff determined that they needed to plan and conduct fire drills regularly, check smoke alarms weekly, and even go so far as to record weekly checks of the batteries in flashlights and inventories of emergency candles. It seemed every detail required monitoring and record-keeping by staff.

> [Staff] need to keep a record of the paracetemol being handed out. If [a registration officer] came in and 70 of 100 tablets were missing, we need to be able to account for them. Even Lemsip...everything must be recorded.

Given the variety and tone of the expectations placed on staff by both themselves and the agency, it is hardly surprising that concern for relationship development failed to find its way onto the priorities list. It seemed all of staff's time had been allocated to other things, which staff and the agency tacitly agreed were things that should not be put aside in favour of the men's social development. Even more worrying was the assumption that many household tasks should be undertaken by the men, despite the amount of hours these tasks would collectively involve in a typical week.

> I think the men should be involved [in carrying out the cleaning rota] on their home-base days.
>
> Yes, work it out so everyone gets a fair share, including the men.

Sometimes, the balance of a tenant's lifestyle was clearly ignored, and consequently, where the men lacked social activities, it was presumed acceptable to fill in their time with more domestic chores.

> Ralph has too much work to do on his home-base day.
>
> He could split the work up. Why must he do it all in one day? The men sit around two days at the weekend and are bored...so Ralph could do the other half of the work then like washing and ironing.

Such moves were reinforced by the fact that staff felt it was unfair to them when the men didn't participate equally in domestic chores.

> [The bathroom] is being cleaned by staff.
>
> Why aren't the men doing it?
>
> How about staff do it on their early shift with help from the men on their home-base days and at weekends?

There seemed to be no limits on the amount of time a tenant would be expected to spend on household chores in a typical week. As new tasks were identified, they were simply 'piled on' to what was already expected. In retrospect, it seems the 'not enough time' explanation often raised by staff to justify their lack of attention to relationship development, became an equally relevant issue for tenants. They too had developed an agenda which, if one assumed *must* be attended to before pursuing social opportunities, appeared likely to preclude establishing a significant social aspect to their lifestyles.

What was ultimately most troubling about discovering the underlying emphasis on functional independence in the variety of things which staff did, is that (when questioned about this focus) staff were quite clear that a significant increase in such independence would hardly be likely for the men.

> [The men] would never be totally independent...I think the possibility ...is quite remote...I don't think that will ever happen...They are much better at things but you can never leave them. They need supervision.

Despite holding these views, staff continued to spend significant amounts of time with the men working on household skills, while this agenda clearly detracted from the amount of time they subsequently had for pursuing relationship network development. In retrospect, the fact that staff had clearly embraced a functional and

home-based agenda was confirmed by their uncanny yet consistent stance on when to use persuasion and encouragement with the men, and when to allow free choice to prevail.

9. A tendency to selectively use persuasion and encouragement

The reader will recall from Chapter Six that one staff member talked about the agency's implicit, if not explicit, support for what was described as a "let people do what they want" ethos. This comment was made in light of the tensions around staff proactively "motivating someone to form a relationship." In other words, staff couldn't force people to develop new relationships if they also subscribed to the view that free choice for tenants should prevail. While the portraits demonstrate quite clearly that motivation to form new relationships did not seem to be a significant problem for Gary, Roger or Ralph, it seems the emphasis on choice was still relied on by staff to justify their lack of more proactive interventions to facilitate relationships.

In considering the evidence and thinking about a continuum around the concept of choice, it became clear that staff were likely to adopt one of three possible approaches:

1. Using coercion
2. Using persuasion or encouragement
3. Acquiescing to the men's choices.

The dichotomy surrounding which option staff typically adopted in regard to relationship issues, and which they adopted in regard to other issues, evolved as a

significant indicator that offered a further explanation for the poor relationship network outcomes. Evidence suggested that, in terms of social opportunities or relationship development issues, staff were likely to yield to tenants' choices, rather than adopt a position that involved either persuasion or encouragement. Two telling comments from staff were:

> I don't know why Gary doesn't go to church here. We assumed he wanted to go because he went in the past. I think its because he likes his long lies, and he never mentions church so...[staff don't mention it either].

> ...but its difficult, if the suggestion [to invite somebody to his house] didn't come from Roger, we'd probably never think of making that suggestion.

Indeed, positive persuasion or encouragement on relationship issues was sometimes seen as bad practice.

> Its like the wedding Ralph was invited to. He said no, but we kept asking him til he said yes. We shouldn't do it...we should just give him one choice and stop repeating it. If he RSVP's no and then changes his mind, that's just hard lines.

Where staff did use persuasion, it was largely to *stop* or *discourage* the men's involvement with other people.

> I recall how much Roger liked Frieda when she came to work here. I discouraged him after awhile, because he was phoning her after she'd left working here. I told him to let her get in touch with him.

Sharply contrasting this was the mass of evidence that showed how staff regularly used both persuasion and encouragement in dealing with a range of other issues that arose for tenants. A selection of examples are shown in Figure Ten.

Figure Ten

We **need** to help him plan a budget for each week, and **suggest** he bank some of it.

I **made** [Roger] get up but I could have left him sleep on.

We should **tell** [Roger] he is so tired, he needs to sleep more because his schedule is so demanding....we should **encourage** him to go to bed early.

We need to **encourage** Ray to use his new helmet and new glasses ...and to wear his glasses at appropriate times.

We should **encourage** the men to [clean the bathroom].

The men **should** be having a light meal at night if they have a big meal for lunch.

We **should be directing** people toward the lo-fat and lo-sugar in the shops...

Just try and **persuade** Ralph not to go round to the shops.

(emphasis added)

While some staff claimed "they can't make the men do or not do things", others recognised that with persuasion or even encouragement, the men would rarely refuse:

> You know well fine there would be no objections from the men to anything...The men have been controlled all their lives. Now its not as obvious but its still happening; they are being controlled more invisibly now. Its done more tactfully - called persuasion - its done in a way that makes it look like their idea. Its control through suggestion really...Right now, most things [that happen] are suggested to the men by staff.

Given this reality, it seems likely that in the absence of persuasion or encouragement, little development in a particular area might be expected to occur. The evidence certainly suggests this was the case. The problem was not so much around responding to people's choices, as it was about taking the view that persuasion and encouragement was somehow inappropriate, despite it being considered appropriate in most every other lifestyle area. Taken to its extreme, what resulted was a staff team that *waited to be asked.* For example, the staff team waited for Gary to say he wanted to go to Church, and since he never said this, he never went.

Although coercion would never be considered an acceptable approach to supporting people with intellectual disabilities, the 'appropriate' use of persuasion and encouragement can be debated endlessly. While some may object completely to such methods being used in the course of providing support, what I am raising here however, is not a debate about whether these types of support should or should not be used. Instead, I am raising the reader's awareness of the evidence that suggests the staff team in this study used persuasion and encouragement *in a specific and selective way*; and I am pointing out that on reflection, this seemed to demonstrate that staff were not as invested in outcomes around relationship development as they were in outcomes around other life areas.

10. A tendency for staff themselves to create some of the most significant obstacles to facilitating relationship development

There are obstacles to *facilitating* relationship development and obstacles to relationship development itself. In considering the role of staff, I am concerned with the obstacles to facilitating relationship development. With this in mind, four

fundamental obstacles (to the positive facilitation of relationships by support staff) that arose in this study were directly attributable to the staff team itself. These obstacles included:

a) a tendency to make negative assumptions about the people with intellectual disabilities being supported;

b) a tendency to make negative assumptions about members of the wider community;

c) being unwilling (or unable due to agency policy) to leave a tenant at home alone in order to pursue relationship-building; and

d) a tendency to react to volunteers' presence by reducing effort.

Taken together, these fundamental assumptions demonstrated that a basic lack of hope about the potential, and complacency about the need, for positive change pervaded. I will begin with the negative assumptions staff expressed about the intellectually disabled people they supported. The majority of the evidence was related to Ralph, whose portrait intimated the struggles he faced around his relationship network.

> Ralph's quite good at playing people off...He tries to get away with it when other staff are on....he's mucking people about.
>
> Ralph's pretty nosey...he hovers around...he gives you no space. It's really heavy going; he follows you everywhere.
>
> Ralph doesn't like women...He expects people to piece together his words... he's gotten a lot more lazy since he moved here.
>
> Ralph's acting like a bully...he thinks he's the boss around here... he expects praise for everything...its definitely a power thing.

In some ways, the struggles Ralph had around his existing relationships, particularly those within the project, caused staff to adopt a largely negative attitude about him as a person. This surely influenced the comfort level staff felt about expecting and

pursuing positive relationship development with members of the wider community for Ralph. In addition, the negative undertones sometimes caused staff to assume the worst about the men's own pursuit of relationships.

> Are [the men] getting over the top with Walt and Heather?
>
> I spoke to Heather and she said it was not a problem, and if it was, she would say so.
>
> I spoke to the woman who runs the shop about it. She's quite happy about Ralph visiting.

This evidence illustrates the problematic notion of expecting staff to facilitate relationships for people who they themselves found it difficult to appreciate. Even more critically, this evidence illustrates the unacceptability of tenants relying so greatly on staff (who hold these attitudes) as their primary sources of security.

Compounding this was staff's view about the people with whom the men had contact. Despite repeated comments, based on practical experience, that the local geographic community and the men's acquaintance relationships were indeed positive (see Figure Eleven below), staff were reluctant to expect such hopeful beginnings to develop into more significant relationships.

Figure Eleven

> I think people would go out of their way to help if they saw the need...my experience so far in Trixdent is that people do try to be friendly.
>
> Most of the people around here do know them now and will talk to them as people.
>
> Charlotte has been very good from the [first] minute we've been here ...and the woman in the bakers is always pleased to see Gary.
>
> The taxi drivers have been great. They always take particular care with the men in getting them where they are going and sorting out the money.

Despite the examples introduced previously of crisis situations where people responded positively to requests for assistance, staff continued to think first of disability connections rather than realising the potential of the community that existed around them. Nowhere was this more obvious than when staff planned for the possibility of fire.

> In an evacuation, the guidelines say...once out [of the house] we should go to Roger's and contact the agency headquarters to get the senior staff on call to arrange accommodation.
>
> That's all dependent on getting into Roger's. This weekend, he's not there.
>
> Well, you'd need to get his key and go into his house.
>
> Worst scenario, go [across town] to Dodden Gardens.

It seems that without justification, staff assumed they could not rely on the local neighbourhood. Where Roger wasn't available, staff planned to go to the nearest group home.

There were a number of other examples where staff seemed to assume the worst of the local community. They sometimes raised fears about the community that had little relevance to the reality of their experiences. For example, staff were concerned about the tenants' benefit money being stolen from them after they collected it at the local post office.

> I'd rather the money is stolen from me than from the tenants.
>
> The trauma would be quite bad for the tenants.
>
> I'm quite disappointed that you all think you'll get mugged on the Trixdent High Street. I live in Trixdent and I don't hear about people getting mugged.

In some cases, they also assumed the worst of people already apart of the men's networks.

> M. told the staff at the day centre that Roger would be picked up today for a doctor appointment.
>
> Staff sent him home in a taxi anyway.
>
> He probably told them but they just ignored him.

The combination of negative views about the men and the community of people with which they had contact, resulted in staff adopting a view that more proactive approaches to developing relationships might 'scare off' people who were becoming involved in the men's lives.

> Jason was never told about Gary having epilepsy. We didn't' know Jason well at the time...didn't know if he'd just walk out [if we told him].

Consequently, a general reluctance to expect and assume that relationships could be enhanced appeared to develop among staff.

> I think people don't want to get involved - don't want the relationship to become a friendship. That's a horrible thing to say but I don't think there's people out there...say I was to suggest to Roger to invite somebody from the day centre up to his house, but then Roger says that to somebody - its then putting pressure on that person then which maybe Roger hadn't thought about...I suppose its really about [being afraid to scare somebody off] because for Roger's sake, we don't want him to lose what he's got.

As a collective, it seems staff sometimes sabotaged potential developments before they had a chance to materialise.

> What about a day gardening with Paul?
>
> It might be worth seeing if P. would accept Ralph on a work placement.
>
> P. is not paid to teach tenants.
>
> We can only ask him.
>
> Yes, but I wouldn't put money on it.

The negative assumptions about the men and the people with whom they had contact were only further mirrored in staff's assumptions about their own role. As the missing link in facilitating relationship development, it seems staff viewed their own potential to be present with equal hopelessness. In addition to the issues presented previously in Theme 4, where staff made assumptions about the likelihood of their absence due to both inadequate staffing levels and a more fundamental belief that this was a more favourable scenario anyway, they also furthered this assumption of absence through their unwillingness (or inability) to leave a tenant at home alone while they went out with another. Where inadequate staffing levels typically meant there was only one staff member on shift to support the three men, this left them with three options in broadening their efforts to facilitate relationship development: they could support all three men to go out somewhere; they could leave two men at home while supporting the third on a one-to-one basis; or they could support all three men at home. Few staff felt comfortable with the idea of taking the men out in a group, both because it was unhelpful socially but more because it seemed to involve significant risk.

> ...it's usually all three men and staff so we're a bit like a social group; [therefore] people don't tend to interact with us and we don't interact with them.

> Last night I was on myself with the three guys. Now I could take [them] out in my car, which would be the only way I would feel I was providing them with a safe way to get out. I certainly couldn't feel safe with three of them on the bus.

As well, staff also felt the risk too great to leave two of the men at home and go out with the third.

> It's piece of mind. I don't think [saying we can't leave the men more than a certain length of time] makes any difference. It could be one minute, and [Ralph] could take a fit.

The agency seemed to engender, if not encourage, this approach by staff.

> ...the [agency] policy at this point is that we can't leave a tenant alone. In the job description it says we are responsible...the wording is worrying...If something goes wrong...we get blamed [by the agency].

Consequently, the least-risk option for supporting all three men - staying at home - was typically pursued. This option was also the least likely to facilitate relationship development. Staff clearly saw relationship development as an initiative that did not justify risk-taking like more functional agendas would.

> I would maybe go down to the doctors or go and do the shopping, leaving Ralph and Gary; but I certainly wouldn't go to a social activity.

Finally, it seemed that the presence of volunteers sometimes engendered an attitude of complacency among staff toward their need to make additional efforts around relationship development.

> I still would like to see Gary get involved in a regular weekly thing [where he could meet people] but because he's been going out with his volunteer so much, the need for this doesn't seem so apparent.

Ultimately, the tone of pessimism around the men and their communities, combined with staff's inability to take risks to work on relationship development clearly established a cautious, if not actively resistant stance toward taking a more proactive role in facilitating relationship development. This was then coupled with a sense of complacency that appeared to result from volunteer involvement. Consequently, positive acquaintances became nothing more despite the passage of time. In retrospect, the evidence suggests there may have been many examples where staff simply let their pessimism get the best of them. Yet it seems unlikely that staff were operating in a vacuum. They were likely to be influenced by the views and actions of others - particularly the agency that employed them and the community members alluded to previously. In trying to determine the impact of these third parties, I turn now to considering the evidence of their activities.

B. EVIDENCE OF AGENCY AND COMMUNITY IMPACT

In considering the likely possibility that staff *did not act independently*, testing the idea that either the supporting agency or the wider community may have contributed to staff's inadequate support for community integration seemed important. In undertaking this, a sharp contrast in the evidence developed.

1. Agency impact

The reader will recall that a number of barriers to facilitating relationship development that can be attributed to the agency which have already been mentioned. Things like giving staff the duties normally performed by a project leader, emphasising the functional side of registration, focusing on task analysis, and providing inadequate staffing levels are all actions and agendas which obviously undermined work on facilitating relationships.

Staff often cited staffing levels set by the agency as the primary barrier to their facilitation of relationship networks. They noted that the men simply didn't get to do things that may have led to relationship development because staff support was not typically available, particularly for individualised opportunities. It seems the agency's operational policies did appear to mitigate against redressing this reality in two distinct ways. First, as alluded to earlier, the agency stance was one of 'protective caution' when it came to staff leaving a tenant at home in order to support another tenant in an activity. Second, in pursuit of efficiency, the agency

adopted a policy of redirecting staff to other projects when there was more than the minimum cover available.

> If I put two [staff] down on the rota, [the project leader] automatically moves one of them to Dodden Gardens.

It became clear that as the men progressed functionally, the agency judged their need for staff support to decline in light of this.

> The more you tell [agency managers] how well the men are doing, the more they say we can do with less staff. You're afraid to do yourself out of a job, and do the men out of what they still need.

This staff member's view was based on the project leader's comment in an earlier meeting: "You all say how much the men have progressed so it makes sense that they don't need two staff on."

What the agency did do to compensate however, was start a volunteer programme. Abrahms (1989) is one of a number of authors who concludes that the use of volunteers is an effective way to enhance the relationship networks of people with intellectual disabilities. On closer inspection however, the volunteer programme failed to produce such results for what proved to be very obvious reasons. In addition to the agency allowing if not encouraging volunteers to become staff, it was clear that their purpose was *not* to widen people's relationship networks.

> I wouldn't have thought volunteers focus on [widening people's relationship networks]...I've never been aware of that being addressed...I'm not aware of their time together involving much of Jason's own network...I don't hear Gary talking about other friends of Jason's whom he's met. It seems Jason is quite happy just plodding along with Gary. Its always just the two of them when they are going out together. They never say they are going to meet other people.

Volunteers were generally viewed as being involved to assist tenants in pursuing hobbies and activities, and to develop a one-to-one relationship with the tenants. They were not involved to expand tenants' social networks; yet evidence presented earlier suggests that the presence of volunteers caused a complacency within staff in terms of relationship building.

Additional ways in which the agency inhibited the facilitation of relationship development by staff arose largely as indirect consequences of problem-solving in other areas. Many times, the project leader's solution to a problem took no account of the implications such a strategy might have for relationship development. For example, when the project manager discovered an overspend in the monthly food budget, she instructed the staff to stop shopping at the local store they had used since the move.

> We used to do the weekly shopping at [the local food store]. People were getting to recognise the men, staff were very friendly and helpful, and we often saw other Trixdent people we knew there...but that had to stop because we were told the food budget was too high. Now we do practically all the shopping at [a discount warehouse]. The store has a whole different feel and the men don't meet people they know as often in there.

In another example, when staff were concerned over the security of collecting the men's benefit money at the post-office, the project leader suggested they phone the DSS and have it put straight into the men's bank accounts. Fortunately, one staff member realised the social drawbacks of this solution.

> But I think its a good social thing. People say hello to the men and recognise them.

Sometimes, the agency's procedures encouraged standardisation that also inhibited natural relationship-development opportunities. For example, tenants were expected to use professional tradesman from an agency-approved list for work that needed to

be done on their homes. This gave tenants no opportunity to engage (and consequently meet) a local tradesman or to offer the work to a friend or acquaintance already known. In addition, the use of a local pharmacy was rejected by agency managers.

> All the houses are doing different things with ordering drugs... this shouldn't be happening. We're having a full team leader meeting to standardise the system...What we don't want is some houses working differently from others.

In terms of supporting or guiding staff's activities through the provision of training, evidence suggests staff had only limited training opportunities and these did not focus on community integration or relationship building. This reflected the fact that the agency was as preoccupied with other agendas as the staff were. In the 2 1/2 years observed, staff were sent on a manual handling and first-aid course.

Finally, where an agency development worker attempted to make inroads into Trixdent in an effort to establish a network of personal connections with people who could assist with community integration, this work was left unfinished. Yet the initiative made staff feel they couldn't contact local people or places directly because this work was being co-ordinated at an agency level.

> Trixdent has a gardening club...maybe Ralph could find a volunteer to garden with him through them.
>
> That's where this network [the agency is working on] would be helpful.
>
> Its not ready to be accessed yet.
>
> So its okay for us to contact them directly then?

Many problems with the agency, particularly in relation to inflexibility, extended to other agencies as well. The ATC bus represented a vivid example of many agencies'

general disregard for relationship development.

> They all have their seats and you can't sit on another seat or sit next to anyone... I have heard the escort saying 'you sit there.' If somebody tried to break out of the mould, I don't know what would happen.

The short-stay service attached to the agency at the centre of this study also allowed their work to inhibit natural relationship development.

> Liza wants to spend more time with Gary and vice versa. The manager at the short-stay service said they make plans ahead of time for people coming in so if Gary phones up to arrange something with Liza, it ruins their plans...The manager also said it would be easier if Gary and Liz saw each other mid-week rather than at weekends because that is when the outings are arranged.

2. Community impact

Here is where the great contrast in the evidence materialised: not only a contrast in content, but to a much greater extent, a contrast in amount. In considering what evidence may have existed, which suggested that the wider community or people already in the men's relationship networks created barriers to the facilitation of relationship development, I found very little evidence in this regard. Except in the case of Ralph's relatives and the men's disintegrating relationships with other people who also had intellectual disabilities, the assumptions held by staff about people being unwilling to see these relationships develop, appeared largely unfounded. This did not guarantee however that there would have been no reluctance. In reality, it seems more often than not, staff never got far enough in the process of facilitating either the enhancement of existing relationships, or the development of new ones, to accurately assess whether community members would say or do things

that would either positively or negatively effect staff's efforts and the subsequent outcomes that accrued for tenants.

In retrospect however, there was more evidence to suggest staff may have been 'pushing on an open door' than not. For example, the reader will recall the positive reactions of people to the crisis situations that developed, and staff's positive comments about the wider community based on their practical experiences. Likewise, the positive relationships that the men had built up with neighbours and their participation (without incident) in a range of activities provided additional evidence that reluctance may not have existed. This positive evidence was hardly offset by evidence to the contrary.

Overall, in considering who may have contributed to the nature of staff's impact upon the poor relationship network and community integration outcomes that evolved for those they supported, it seems the balance of evidence (interpreted cautiously) suggests that it was more likely to be the supporting agency, rather than the community, which influenced the reality of the staff team's role in this regard.

C. GENERATING EXPLANATION FROM THE EVIDENCE

Introduction

As a consequence of being aware, throughout the process of data analysis, that the central intent in this study has been to offer an explanation of the community integration outcomes documented, I recognised the importance of going beyond a

simple exploration of the roles of direct support staff, the sponsoring agency and the wider community. Although I have, to this point, illustrated in detail the variety of attitudes, assumptions, actions, and activities which all appeared likely to have some bearing on the community integration outcomes that evolved, these discussions do not include a coherent explanation, which ties the variety of identified themes to each other, and then to the documented community integration outcomes.

My approach to developing this explanation consequently involved posing questions to myself about the findings I had generated thus far from the data. As each question was answered, and I confirmed the validity of the answer by referring back to the evidence in a grounded approach, I then posed another question about that answer - in a process that continually extended the capacity of the evidence to generate a provisional yet coherent explanatory framework. I describe the *nuts and bolts* of this process, and the results it generated, here.

Beginning to explore the evidence from an explanatory perspective

I began by recognising that, although the discussion around each of the themes related to staff's attitudes and activities presented in this chapter has been individually informative, these themes nonetheless remained *discrete*. In other words, they had not been tied together in a way that would suggest how the pattern of staff's attitudes and activities ultimately coalesced to demonstrate the cumulative impact of the staff team. I therefore began the task of developing explanation by considering the various discrete themes as a collective whole. I refer the reader to Figure Twelve which summarises these themes.

Figure Twelve: Summary of the Discrete Themes Identified

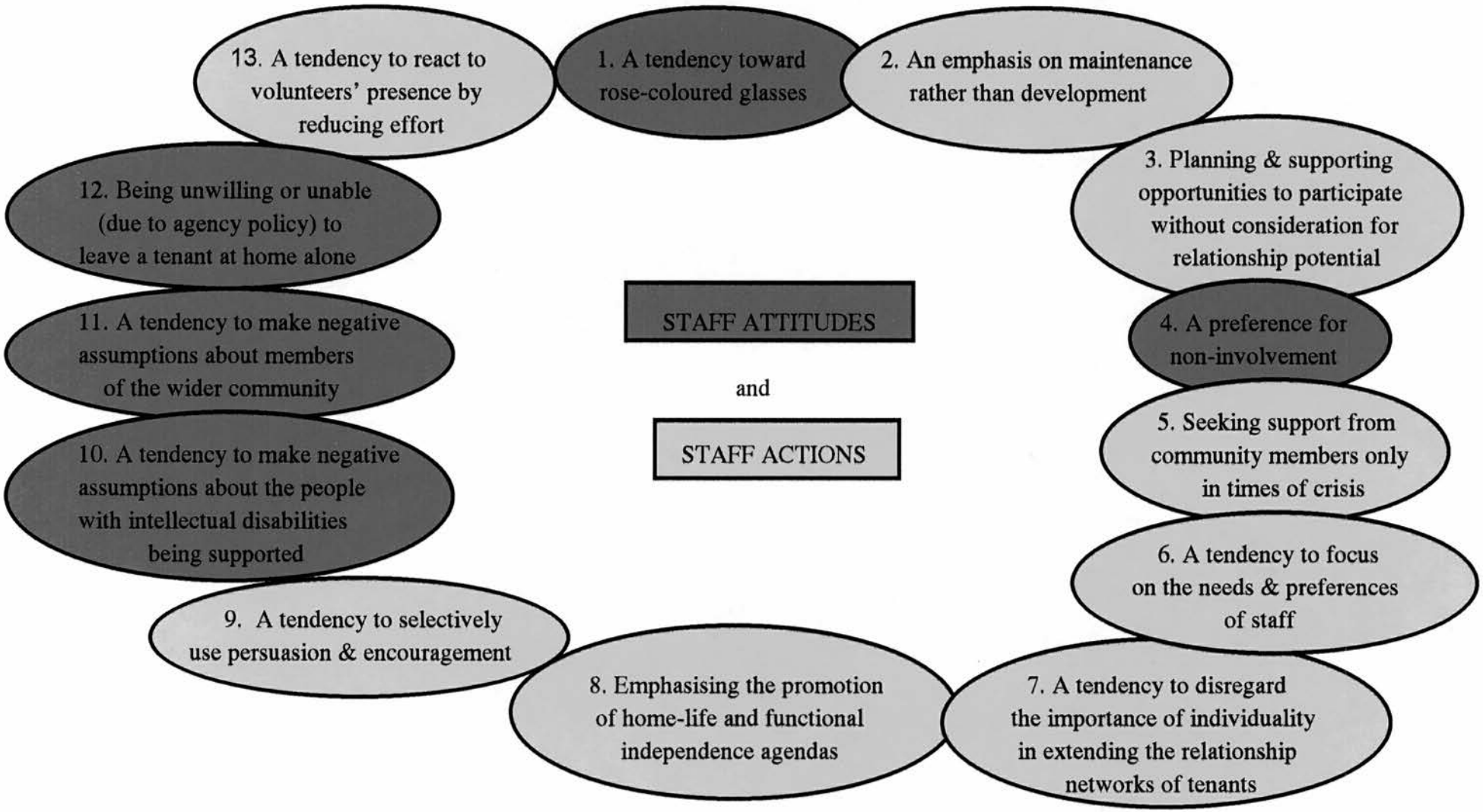
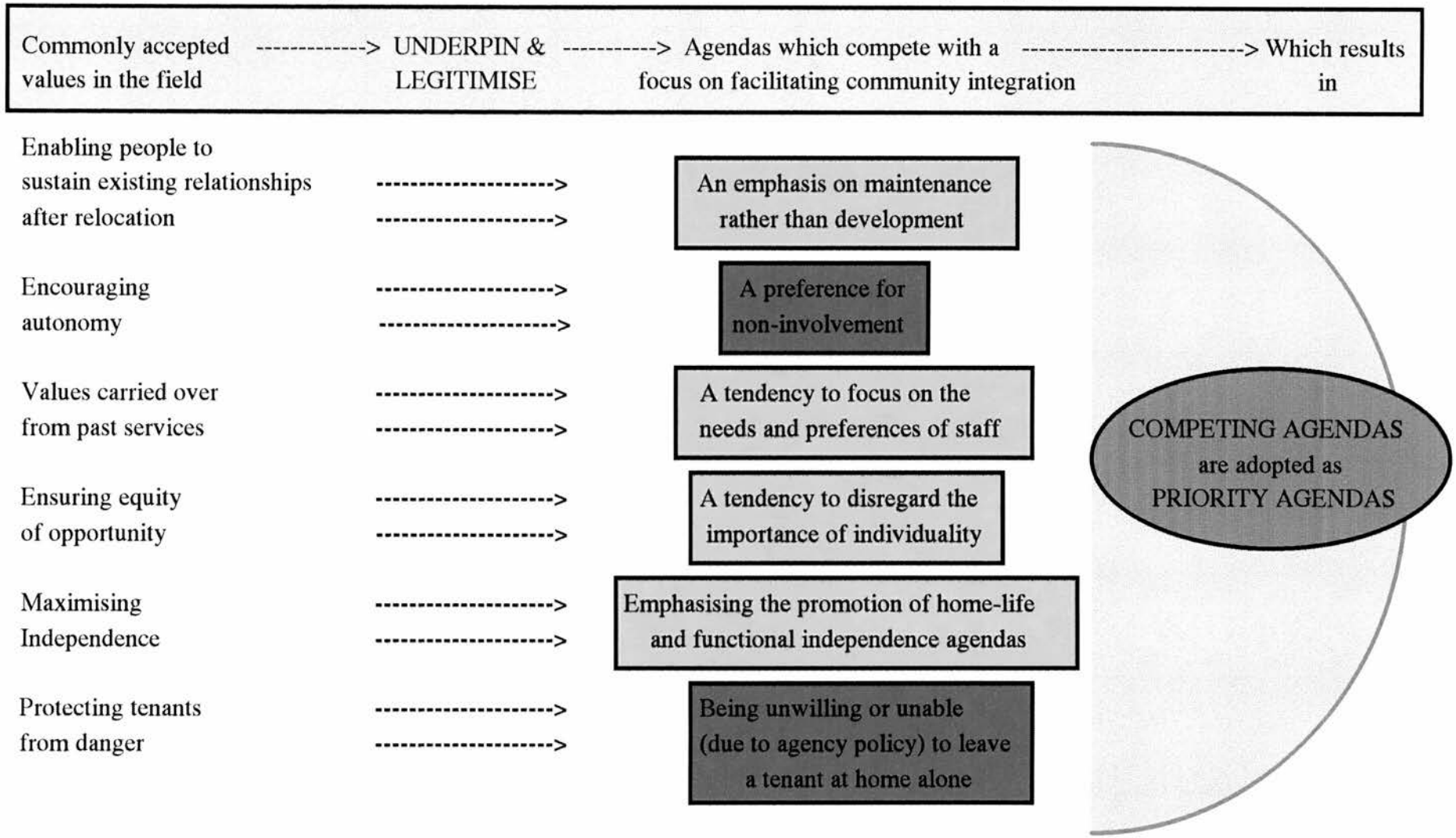


Figure Thirteen: Discrete Themes related to Competing Agendas



but was not underpinned by a commonly accepted value in the field was (6): *a tendency to focus on the needs and preferences of staff.* This agenda can be more accurately described as a manifestation of the values associated with past services, where it was often the case (particularly in institutional settings) that the whole of the support routine was designed to suit staff rather than residents. The evidence suggests this value has been carried over from past service models to re-surface as an agenda in community-based residential services. Ultimately, as Figure Thirteen illustrates, the six discrete themes identified were underpinned and legitimised by acknowledged values in the field, and this resulted in these competing agendas being adopted as priority agendas by the staff team studied.

Figure Fourteen, which deals with the unifying theme of *complacency*, reveals that the competing agendas identified in Figure Thirteen each contributed to the complacency that staff demonstrated toward relationship-building and community integration. In addition, three other discrete themes were identified as being strongly related to the unifying theme of complacency:

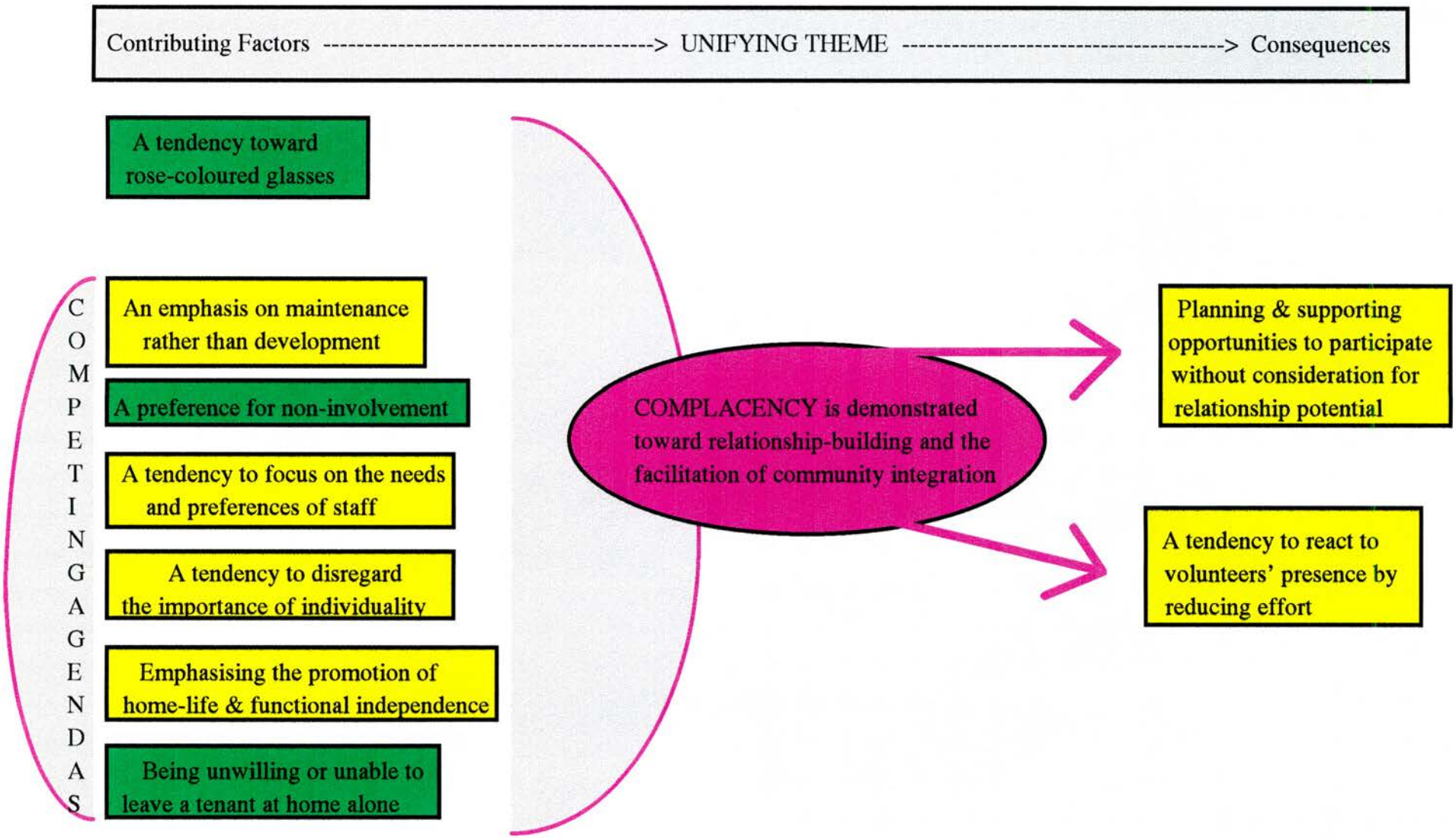
(1) A tendency toward rose-coloured glasses;

(3) Planning and supporting opportunities to participate without consideration for relationship potential; and

(13) A tendency to react to volunteers' presence by reducing effort.

Among these, it proved possible to distinguish between those themes which appeared to *contribute* to the complacency and those themes which developed as *consequences* of this complacency. Figure Fourteen illustrates these distinctions, which provide a more definitive representation of the evidence, and thus further facilitated my understanding of the explanation that was evolving.

Figure Fourteen: Discrete Themes related to Complacency

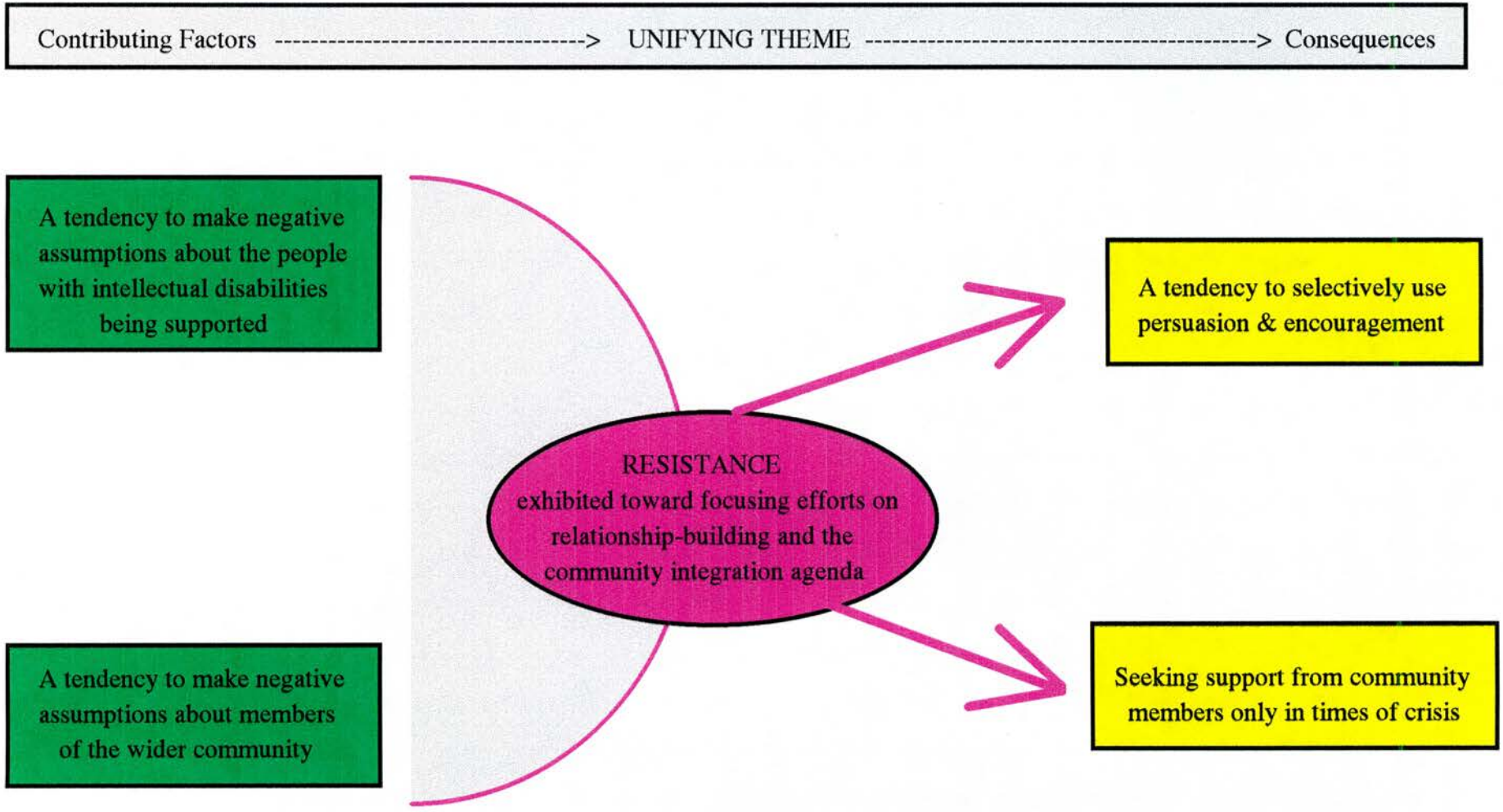


For example, while staff's rose-coloured glasses perspective offered justification for adopting a complacent stance, once this stance was adopted, the presence of volunteers reinforced the comfort staff felt about reacting with complacency to the tasks of relationship-building and facilitating community integration.

Finally, in Figure Fifteen, the discrete themes that were most strongly related to the unifying theme of *resistance*, are illustrated. Again, it was possible to distinguish between those themes which appeared to *contribute* to the resistance and those themes which developed as *consequences* of this resistance. Figure Fifteen demonstrates that staff's resistance was underpinned by the negative attitudes they held about those they supported and members of the wider community. The figure also reveals that these attitudes had a profound significance on the work that staff did in terms of relationship-building and community integration. The tendency to selectively use persuasion and encouragement, combined with staff's decision to seek support from community members only in times of crisis, meant that there was a lack of encouragement by staff, *both* of the intellectually disabled people they supported *and* community members, to become involved with and engage each other in ways that would make relationship development a possibility. This realisation that in fact there was a significant lack of effort being exerted on both fronts, enabled me to recognise the critical role that staff's resistance ultimately played in the disappointing community integration outcomes that had been demonstrated.

Although in considering these three figures, the reader will recognise that for the most part, each discrete theme was assigned to only one unifying theme, it is important to clarify that the reality was not so black-and-white. Indeed a number of themes seemed likely to be related to more than one unifying theme; but I took the

Figure Fifteen: Discrete Themes related to Resistance



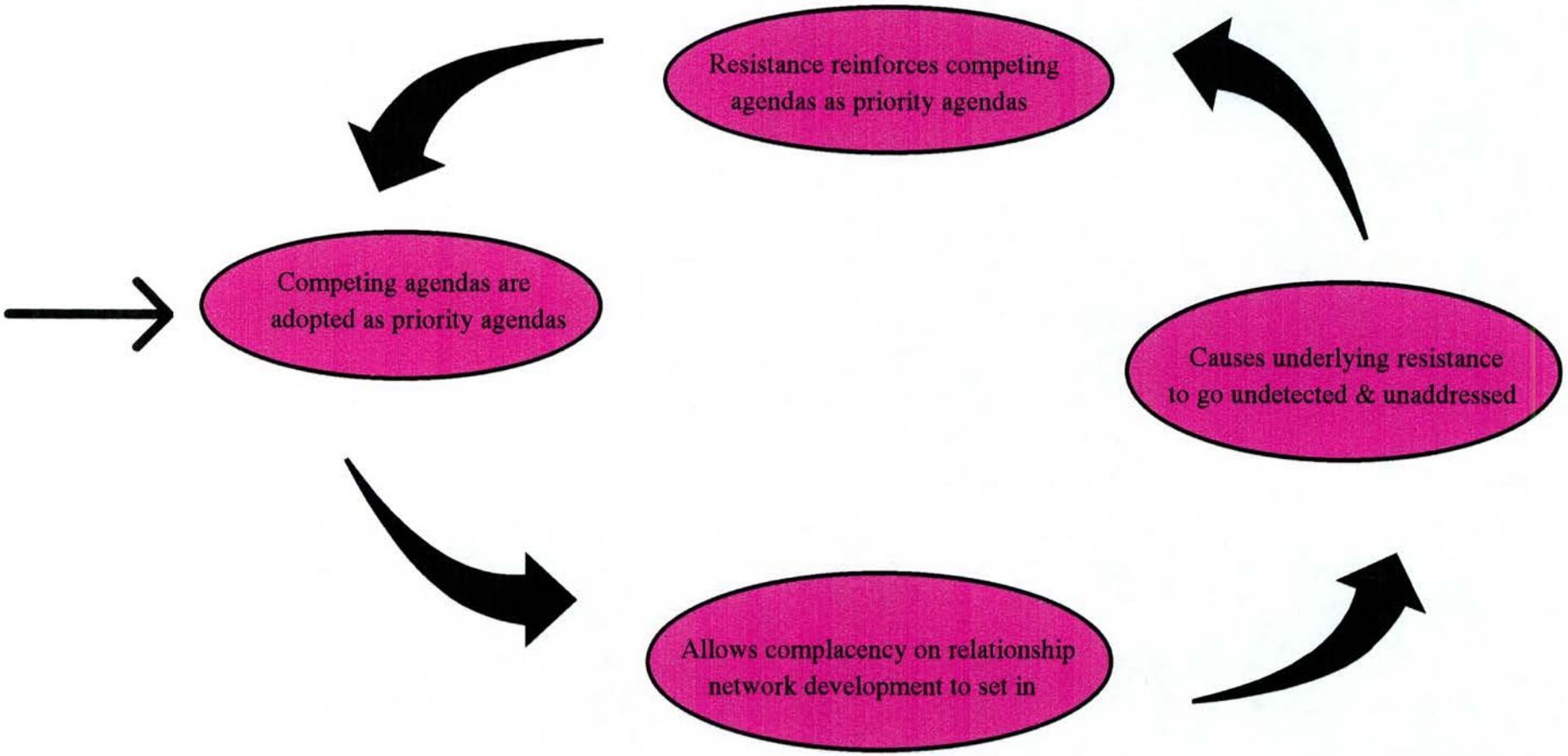
decision to focus on illustrating the correlations of greatest strength that existed between the discrete and unifying themes. This was not however, meant to imply that other correlations did not exist.

Drawing explanatory conclusions

Having identified the relationships that existed between the discrete themes and the three unifying themes, the question I then posed to myself was how the three unifying themes were tied to each other and subsequently, to the documented community integration outcomes. Within the process described above, I had already come to the conclusion that the competing agendas contributed to the tendency toward complacency that staff demonstrated in regard to relationship-building and community integration. The task that remained was to incorporate the unifying theme of resistance into this.

By returning to the evidence, I recalled that the resistance staff exhibited was something I had to 'draw out of them' in interviews: for the most part, its presence was not obvious. Therefore, I concluded that a logical explanation for this was that one of the other unifying themes had somehow caused this resistance to go undetected. In asking myself how the competing agendas which staff adhered to, and the complacency they subsequently demonstrated, were likely to cause their underlying resistance to go undetected, I recognised that a causal pattern was emerging - and indeed this pattern suggested itself as a cyclical pattern, which given the strength of the conclusions thus far, could be deemed a vicious circle. Figure Sixteen illustrates this vicious circle, demonstrating the relationship that existed between the three unifying themes.

Figure Sixteen: The Vicious Circle



Within the circle, staff's tendency toward complacency, that resulted from them adopting competing agendas as priority agendas, not only explained why poor relationship network and community integration outcomes could be expected, but also *disguised* the attitudinal resistance toward these agendas that existed amongst the staff team as individuals: a finding which further explains the poor outcomes that have been documented. Ultimately, the circle both accurately reflected the evidence I used as the basis for developing the explanation, and brought that evolving explanation to an ultimate conclusion.

The significance of the provisional explanatory framework

Overall, the provisional explanatory framework includes all of the figures and ideas discussed previously; but it is ultimately epitomised by the vicious circle. Through this framework, I am contending that the pattern of staff attitudes and activities can explain both how and why the staff team were clearly a significant barrier to relationship network development and increased levels of community integration for those they supported.

While I am making a strong indictment of staff, two considerations should also be taken account of when putting these findings on staff's role into perspective. First, it's important to note that none of the three unifying themes, including that of resistance, appeared to be wilfully created by staff. This was a staff team which the evidence suggests neither consciously intended nor planned to be a barrier to relationship network development. In some ways, the interviews demonstrated that staff were hardly aware of their own attitudes of resistance. As well, they displayed

a number of very positive attributes that demonstrated their good intentions:

> -They demonstrated a consistent and significant commitment to non-segregated opportunities for the tenants to participate alongside of the wider community's members;
>
> -they demonstrated a strong determination to find the tenants opportunities which would enable them to reduce attendance at the adult training centre;
>
> -they demonstrated a commitment to finding tenants integrated opportunities which reflected each man's unique interests, rather than simply 'slotting them in' to what was available;
>
> -they fought against cuts in staffing imposed by the agency;
>
> -they involved the tenants in their own personal lives to a limited extent, staying with friends on tenants' holidays or having tenants round to their homes from time to time;
>
> -some of the staff pushed themselves to do more in the area of community integration than was typical in their own lifestyles, like developing limited relationships with the tenants' neighbours where they had little or no contact with their own neighbours;
>
> -and finally, they worked for a number of years without leadership or support from a project leader, while expectations increased from central management, and resources remained unchanged or indeed reduced.

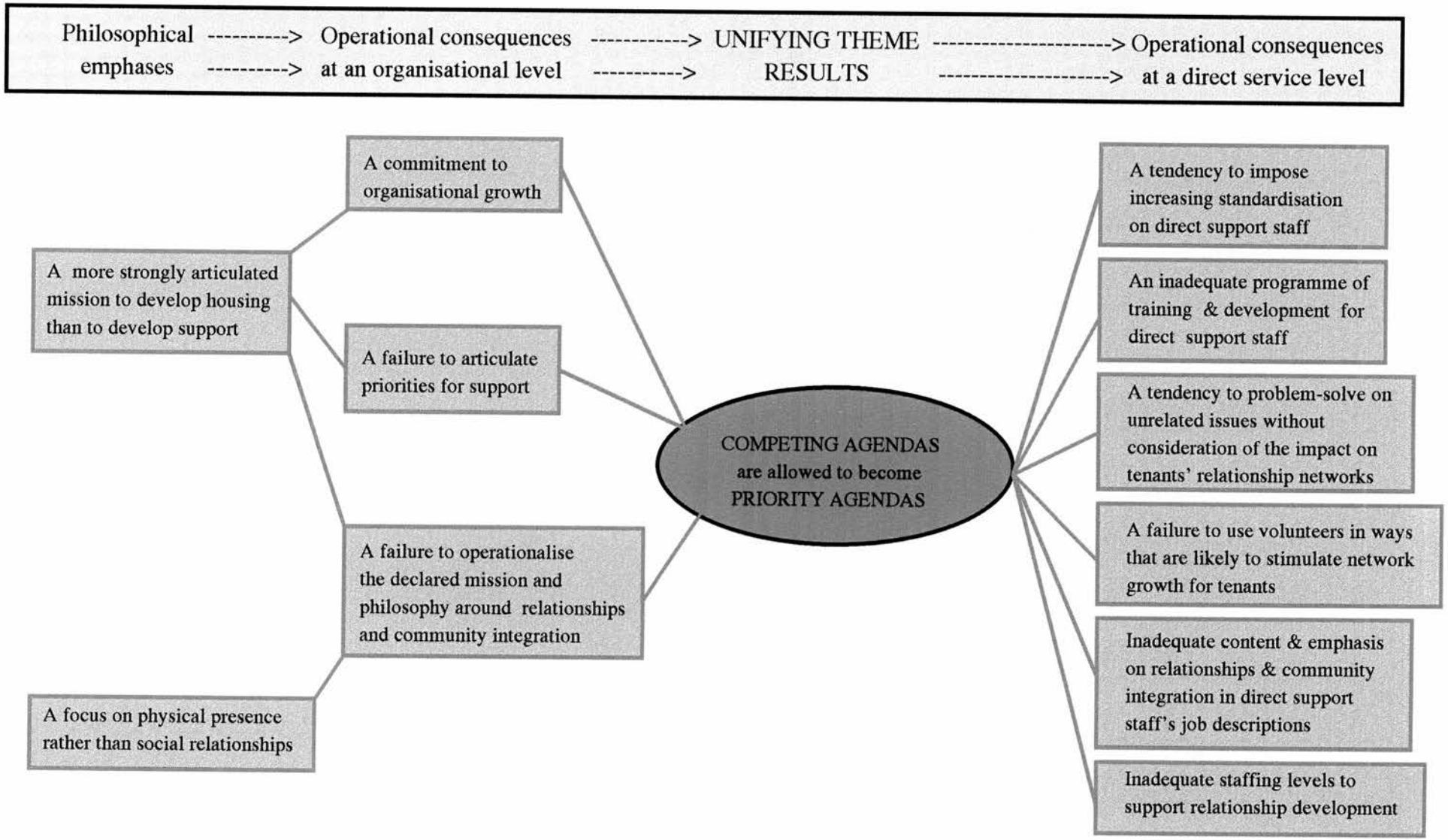
Although these examples are clearly evidence of positive intentions and actions, the fact that more positive community integration outcomes did not accrue suggest that staff failed to confront their more deep-seated and often unrecognised resistance to intentionality around relationship development. Consequently, as I argued above, staff remained more of a barrier to, rather than an instigator of, relationship network development and community integration for those they supported.

The second important consideration that must be addressed is the question of whether the vicious circle that exemplifies the attitudes and activities of staff existed independently, or was supported by external factors: namely, the sponsoring agency or the attitudes and actions of community members. While the extent of the evidence about the attitudes and actions of community members was deemed

inadequate to draw clear conclusions in this regard, the evidence in relation to the sponsoring agency did offer a way to determine whether the agency turned a blind eye, attempted to break the vicious circle, or contributed to the strength and stability of the circle.

Since it has been argued that the vicious circle began with the adoption of competing agendas as priority agendas, I explored the evidence related to the sponsoring agency to determine whether it demonstrated a pattern that would ultimately support or mitigate against these agendas becoming priority agendas for direct support staff teams. Figure Seventeen outlines the evidence in this regard, drawn from Chapter Six and previous discussions in this chapter. It is clear in Figure Seventeen that the agency's declared philosophical emphases resulted in the failure to establish community integration as either a priority agenda for the organisation, or for the staff providing support to tenants on a day-to-day basis. Compounding this was the variety of operational consequences that resulted from the declared philosophical emphases, which all came to bear on direct support staff, and clearly failed to reflect any concern for tenants' relationship network development. Given this, there is strong evidence that the sponsoring agency both guided and reinforced the adoption of competing agendas as priority agendas by staff, which provided the starting point for the vicious circle that can explain the poor relationship network and community integration outcomes of those being supported.

Figure Seventeen: Evidence of Support for Competing Agendas by the Sponsoring Agency



Lessons learned

In retrospect, the explanatory framework reveals that staff, and the agency which sponsored them, were a greater barrier to, than facilitator of, relationship network development and community integration for those they supported. While the framework suggests that dealing with the competing agendas, and the variety of agency factors which contribute to these becoming priority agendas, would be a critical first step; it also implies that this would only be a first step. If these issues were addressed and as a result, complacency on the agenda of community integration was no longer a tolerable scenario, the agency would then be faced with the attitudes of resistance which many staff hold, but which had previously been masked by the complacency that staff demonstrated and the agency tolerated.

Chapter Conclusion

Overall, the provisional explanatory framework introduced here strongly suggests that the combined impact of the agency and its direct support staff was indeed significant enough to confirm the assertion made in previous literature that residential support staff play a role - indeed this study suggests a very critical one - in determining the nature of relationship network and community integration outcomes for those they support. The findings and conclusions presented in this chapter go further than confirming the significance of staff's role. They offer a detailed analysis of *the exact nature* of that role as revealed by the evidence.

Through this, the study has addressed the principle concern with which it began:

> ...the need to look quite seriously at the nature of the preparation, support and opportunities that staff provide to individuals to become involved socially in their communities and develop relationships.[2]

In addressing this concern, one thing the findings clearly demonstrated is that the Five Accomplishments (as a set of philosophical guideposts) cannot be pursued harmoniously: in this study, it was clear that pursuing one accomplishment implicitly detracted from pursuing another. Although this may not be intended at a theoretical level, it does appear that this is likely to result at a practical level. Most critically, this study suggests the pursuit of competence, particularly around functional, home-based living agendas, often detracts from the pursuit of community participation and presence. Recognising this consequently requires community residential agencies and staff teams to begin to grapple with the need to establish priorities for personal development in the support they provide to tenants. Interestingly, an agency business plan suggests that the director seemed fully aware of the need to consider and establish priorities on other bases.

> We must remember...that every time we commit money in one direction, we make it unavailable for another potential use, and may therefore lose an opportunity which may have been more valuable than the one we chose.

Yet the agency did not adopt a similar stance toward the allocation of staff efforts, and management as well as direct service staff failed to recognise what consequences this would have in practice. Drawing the reader's attention to this issue is not to suggest however that priorities for service delivery did not exist within the staff team investigated. In reality, the priorities, which the evidence showed to exist, did not evolve from the agency's philosophical agenda, but were allowed to arise pragmatically and to some extent, idiosyncratically. Newman

(1968) would conclude that such sharp dichotomies, between the declared intentions of an organisation and the observable practices of its workers, would be the ultimate demonstration of organisational ineffectiveness. Yet despite the logic of this, and the director's own awareness of the essential nature of priority-setting, the agency failed to recognise or adequately grapple with the tensions between pursuing community integration and other direct support agendas in the 2 1/2 years observed.

In reality, it seems that part of the reason why relationship development and community integration had so little success in becoming a service priority was because established priorities appeared at least in part to be based on a spill-over of ideology from past service models used with people who have intellectual disabilities. Few would dispute that in these models, relationship networks and community integration were not a focus of the day-to-day support provided. Ironically, the status of relationships in this agency's agenda mirrors its place in O'Brien's accomplishments list: whether intended or not, relationships is the last of O'Brien's Five Accomplishments and similarly, it had become the last priority for the agency and staff at the centre of this study.

The question then becomes: is this explanatory framework applicable to most residential provider agencies? In an effort to determine to what extent the provisional explanatory framework was indeed generalisable, I explained in Chapter Four that I took the decision to locate four other similar residential projects supported by four separate agencies. In studying these, I conducted a shorter but similarly focused period of investigation designed to reveal whether or not the explanatory framework, and the findings which underpin it, actually held true when other projects and agencies were considered. According to Yin (1994), such

'analytical generalisation' is an important component of effective research.

> **In analytical generalisation, the investigator is striving to generalise a particular set of results to some broader theory... The generalisation is not automatic, however. A theory must be tested through replications of the findings... (p. 36)**

With this in mind, I now turn to the findings from these 'secondary' samples before offering an ultimate set of conclusions in the final chapter of this thesis.

[1] The term "dumping" is one coined by Wolf Wolfensberger in the early nineties to describe how people with intellectual disabilities had been relocated to the community without adequate support.

[2] adapted from McConkey *(et al.* 1982) .

CHAPTER NINE

"Considering Generalisability"

Introduction

It is important to begin by saying this chapter provides the reader with a much abridged version of what would have been a perhaps preferable and extensive walk through each of the four secondary samples, were it not for issues around the overall length of this thesis coming to bear on the writing process. I hope that the reader has benefitted from the extensive walk through the findings from the primary sample in a way that will prepare him/her for the shorter but essentially similar discussion contained in this chapter. In order to effectively summarise the findings and conclusions which evolved from my own intensive consideration of the data from each of these four samples, I have structured this chapter in the following way.

1. A brief introduction to the four projects and the agencies which sponsor them;

2. A summary of the relationship networks and extent of community integration of those people with intellectual disabilities identified from each project, considered through a variety of perspectives that reflects those used with Gary, Roger and Ralph;

3. A review of the themes related to the agencies and the staff teams that arose within these four samples and which were consistent with those from the primary sample;

4. A review of the themes related to the agencies and the staff teams that arose within these four samples but which were different from those identified in the primary sample;

5. And finally, a discussion of the critical conclusions which can be drawn in relation to both the issue of generalisability and the validity of the explanatory framework developed for the primary sample and introduced in Chapter Eight.

The discussion which closes out this chapter leads the reader into the final chapter of this thesis where the implications of the study's overall findings for future policy and practice are discussed.

The Projects and Agencies

Project & Agency "A"

This project was one of thirty-one run by a housing association, whose initiatives spanned eastern Scotland and collectively served over 300 people with intellectual disabilities. The project in question, in place for 3 1/2 years, was typical of the majority of the association's community care initiatives over its 18 years in existence: a purpose-built block of housing, including a 9 person community house and a 3 person 'satellite' flat, all with 24 hour support from a single staff team. In addition, 4 mainstream units were included in the block for people who did not require support.

Project & Agency "B"

This project was one of forty run by a housing association which was involved mainly in central and western Scotland, and which served over 500 people with intellectual disabilities. The project in question, open for 2 1/2 years, was again typical of the majority of the association's projects developed over its 18 years of existence: a purpose-built self-contained housing development, including a 'dispersed' project (a series of one, two and three bedroom flats), one four bedroom

block for people with 'high support needs' and a small number of flats for 'mainstream' tenants who did not have intellectual disabilities. All intellectually disabled tenants were supported on a 24 hour basis. Two sub-groups of the entire staff team worked separately with either the dispersed housing tenants or those living in the high-needs house.

Project & Agency "C"

This project, running for just over two years, was one of thirty staffed houses supported by a private non-profit organisation serving the Grampian Region of Scotland. The organisation, just six years old, served 176 users through a combination of staffed houses, visiting support, day services and respite care services. The majority of people with intellectual disabilities supported by this agency lived in the staffed houses, of which the project in question was largely typical. Four tenants were provided 24 hour support by a staff team in a house that was leased through the local district council.

Project & Agency "D"

This project, in operation 3 1/2 years, was one of twenty houses or flats which were supported by a large voluntary organisation, based in Scotland's capitol city, that had been in existence for 19 years. The sponsoring organisation also provided leisure services to adults as well as children and families, a welfare rights advice service, and a supported employment service. In a model typical of the agency's

supported accommodation intiatives, four tenants were supported by a staff team providing 24 hour cover in a house leased from the district council.

The relationship networks & experiences of community integration for the tenants considered

The content and quality of relationship networks

Overall, the content of the eight people's relationship networks that were considered reflected the fact that they still lived mainly in the world of disability. Five individuals had two *or less* people who were thought to be either friends or intimate friends. A staggering 96% of the friends and intimate friends listed across all eight networks were other people who had intellectual disabilities. One staff member commented:

> I've been here five years and there isn't one tenant who has created a friendship with a person who isn't a professional or doesn't have learning difficulties.

There were numerous comments made by staff interviewed about the quality of the relationships that did exist, and these comments were often negative. They described people's difficulty in getting along, particularly with those they lived with.

> I gathered from talking to A. that his flatmate (intimate friend) will sometimes order him to bed and put the television off...At the Friday club, C. (friend) would totally ignore A...There always has been (a lot of friction around between the tenants) but since R. left, its been worse.

Staff also described some of these friendships as not being of the same quality as their own friendships, sometimes existing more because people were forced to spend time together rather than because these relationships were freely chosen.

> Her friendships are really intimate by circumstance, and I think they share a lot because they live together.

Although not typical, there was evidence of there being good quality relationships between some people with intellectual disabilities.

> Sarah does seem to get on well with David. He teases her and she responds to that. They have a good rapport.

Overall however, evidence clearly suggested that people often had neither the number, nor variety nor quality of friendships that staff typically had. This was largely due to tenants' restricted lifestyles and consequent lack of opportunities to meet new people, particularly people without intellectual disabilities.

The pattern of lifestyles

In three of the four projects (A,B,D) there was a significant lack of opportunities for tenants to become involved in their local communities, and it was even less likely they would have staff support to do this. People generally spent their days and evenings in segregated settings (eg. adult training centres), segregated evening classes (eg. special community education classes), segregated college courses, segregated social clubs (eg. Enable clubs), or their own homes. Even in Project C, where there was limited evidence that tenants were assisted to become involved in their local community, the tenants attended an adult training centre most weekdays, and went to a segregated club every Friday night.

Where tenants did become involved in their communities, the most popular integrated and regularly attended opportunity was the local church, with five of the eight tenants having weekly involvement. The only other example of *regular* integrated involvement concerned one tenant in Project C who attended a mainstream exercise club each week. Other examples of integrated participation of a social nature always involved sporadic attendance (like going to the pub or local social club). And while regular use of more functional community amenities like the bank, shops, and post office heightened the awareness that ordinary community members and tenants had of each other, this offered little if any opportunity for meaningful social interaction.

Staff reported very little if any relationship development resulting from tenants' participation in segregated activities, and it often seemed unlikely to expect this to happen in the future.

> I wouldn't think any of the people Cathy sees at the
> ATC or Tuesday club would be likely to become friends;
> I think she gravitates more toward staff in these places.

Most all of the people encountered were known by the tenant because they had, like the tenant, attended for years. The only exception was one person from project C who made a new friend while attending a segregated college course.

Sources of security and belonging

Not surprisingly, tenants got their feelings of security from staff who were paid to support them, and to a lesser extent from family. This generally represented very little change from their sources of security in previous residences (eg. institutions or

parents' home). People were rarely thought to rely heavily upon their intimate friends or friends for support, especially emotional support. Members of the local community, largely absent from people's networks or listed as nothing more than social acquaintances, predictably offered no feelings of security to tenants.

Although the general absence of adequate alternatives to staff for feelings of security inevitably meant many tenants showed a clear preference for relationships with staff, most of the staff interviewed recognised this was not an acceptable state of affairs.

> **Nowadays there are generally people who care about people with learning disabilities but a lot of those people are professionals and that relationship is certainly not a mutual friendship.**

The local community did, however, contribute to tenants' feelings of belonging where acquaintance-type relationships had developed over time with neighbours, church members and staff at local amenities. In all four projects, however, there were only very limited relationships with immediate neighbours, so tenants' sense of belonging came largely from patronising local businesses and making use of local facilities.

Overall, the tenants considered in each of the four projects had achieved only a modest sense of belonging, while their feelings of security came mostly from paid staff. Alternative sources of security, and indeed even the potential for this, appeared consistently unavailable. Evidence revealed that the passage of time changed this reality very little.

Evidence of positive change in networks over time

The time gap between the two phases of data collection with the four projects ranged from seven months (Project C) to eleven months (Project A). There were very few changes among tenants' intimate friends and friends. Staff reported one person (Project D) added two new friends and a partner, all of whom had intellectual disabilities. Staff further reported two tenants (Project A & B) each had a social acquaintance who became a friend, both also people with intellectual disabilities. There was no change in family relationships. Added acquaintances were typically the result of getting involved in a new activity. The majority of these new activities were segregated, although two tenants starting working at mainstream cafes (Project A & C) while one tenant joined a flower arranging class at the local church (Project C).

Despite the evidence of change, albeit limited, across a number of the tenants' networks, their sources of security remained the same, and with that so did people's profound dependence on support staff.

Conclusions

Without the thick description used to create portraits like those offered in Chapter Seven, the consistency among the relationship networks of the eight tenants in the four secondary projects still speaks for itself. Many of the same causes for concern, that were found in the primary sample, can be garnered:

> - that the extent and quality of these networks were typically limited;
>
> -that there was a lack of significant change over time, particularly in people's sources of security and their friendships;
>
> -that hopeful beginnings were either not happening at all or where they were happening (through involvement in church, integrated exercise classes or employment, and to a more limited extent with neighbours), these potential opportunities for significant relationship development appeared to be leading nowhere.

With such findings confirmed, again the question that demands explanation is why these outcomes could evolve so consistently for eight people with intellectual disabilities, supported by four different agencies and living in four different communities across Scotland. I now turn to considering the evidence which suggests an answer to this question.

The findings from the four secondary samples

Introduction

I set out to undertake a separate process of analysis for each of the sets of data collected from the four secondary samples. I did this in order to maximise the

extent to which independent and uncompromised analysis of the data could be undertaken which would not simply (and wrongly) involve searching for pre-determined conclusions that would support the findings from the primary sample. The analysis process mirrored that used with the primary sample in order to ensure consistency of approach, but with each set of data considered, a new set of themes was created to capture the reality of the particular agency and staff team studied. This allowed for similarities and differences in the findings to come to light, both between the secondary samples and when each of them was compared with the primary sample.

In analysing the data from the secondary samples, I set out to address the same broad areas that were considered with the primary sample, namely:

1) The philosophy and mission of the agency;
2) The actions and initiatives taken by the agency;
3) The activities and initiatives of the staff team; and
4) The attitudes and assumptions of the staff team.

I do not separately address the impact of the actions and attitudes of community members on the staff team in the discussion which follows, as I did with the primary sample. This area is not addressed because the data from the primary sample offered very little evidence of either members of the wider community or people in the tenants' relationship networks acting as a barrier to the facilitation of relationship development by staff. Because of this lack of evidence, the impact of these attitudes and actions did not figure into the tentative explanation I ultimately developed for the primary sample, and subsequently set out to consider the generalisability of in this chapter. I therefore did not plan to consider this issue in the same way that I intended to look at the impact of the agencies on the staff teams

they supported; but the reader will note in the discussion which follows that evidence did emerge about community members which was generally consistent with that found in the primary sample.

Within each of the four broad areas listed above, I grouped the relevant themes which the evidence brought to light and interpreted them with specific reference to the ways in which they impacted upon the relationship network development and community integration outcomes experienced by the intellectually disabled people being supported. Since this chapter is a summary of the process of comparing the findings from each of the four secondary samples with those of the primary sample, there is no space for a separate discussion of the results of each individual process of analysis. I therefore refer the reader to the Appendix (p. 447-454) where the results of the data analysis with each of the four secondary samples are presented individually. These four sets of results and the data which underpinned them provided the basis on which the remainder of this chapter has been written.*

*Note: throughout the discussion, I have referenced the findings by using the letters A, B, C, or D to represent the four agencies as they are presented in the appendix.

Identifying elements of similarity: variations on some key themes

Although none of the secondary samples offered a complete mirror image of the themes identified around the primary agency and staff team, the overall degree of consistency both across the secondary projects and then in their comparison with the findings from the primary project was indeed significant. For ease of

understanding, I will discuss the findings from the four broad areas considered in separate sections.

The philosophy and mission of the agency

Three themes related to the philosophy and mission of the agency, which were identified in the primary sample, arose consistently in all four of the secondary projects.

1. The lack of sufficient operationalisation of the agency's mission, particularly that part of the overall mission related to community integration and relationship networks;

2. The failure to adequately incorporate support for new relationship development and community integration into the job descriptions of direct support staff; and

3. The predominant commitment to an agenda of organisational growth.

The lack of operationalisation of the secondary agencies' declared missions occurred on a number of levels. Broad statements of mission like 'helping tenants to achieve an excellent quality of life and an ordinary life' (C) or 'helping tenants reach their full potential' (A) were often the least operationalised. What was said however about the practical agendas of the agencies in question almost always reflected an emphasis on promoting functional independence and choice. For example, where one agency spoke of enabling tenants 'to have new experiences and increased responsibility in all aspects of their lives' (B), this was operationalised through ten examples, of which personal care, housework and meal preparation were the first three while relationships were not mentioned at all in this list of examples.

Other mission statements were more specifically related to community integration and relationships. Although promising statements like 'striving to provide local community links' (B) and 'allowing and encouraging tenants to be fully integrated into the community' (D) were made, commitment to these could hardly be traced in the concrete tasks and agendas the agencies set for themselves. One agency (D) which promised support for the development of functional skills, promised it could only *try* to ensure support was available for tenants to continue or develop friendships. In addition, three of the four secondary agencies, like the primary one, referred to the *Five Accomplishments* as an operationalisation of their broader missions, and thereby articulated a commitment to a range of developmental agendas for tenants which included relationship networks and community involvement. Yet it was apparent in their more detailed statements of intent that the accomplishment which was consistently least mentioned (and defined) was *participation* (the accomplishment concerned with relationships).

Nowhere was these agencies' failure to operationalise a declared philosophical commitment to relationship network development and community integration more obvious than in the job descriptions they created for direct support staff. These job descriptions were overwhelmingly focused on the facilitation of home-based functional skills development. Cited priorities for staff included the following:

Agency A: 'domestic duties, housing responsibilites, and the improvement of self-care skills';

Agency B: 'personal care, cooking, budgeting, shopping and looking after their house';

Agency C: 'offering care, protection and safety while maximising the participation of (tenants) in household tasks';

Agency D: 'physical care, as well as personal and emotional needs and domestic living skills'.

The job descriptions from all four agencies did however mention either concern for the *maintenance* of existing relationships or the facilitation of positive *intra-project* relationships. Ultimately, neither the primary emphasis on functional skills and home-based tasks, nor the mention of concern for existing and intra-project relationships operationalised the broader statements of intent made about community integration. While a number of staff were aware of the agencies' philosophical intentions with regard to community integration, they were also acutely aware of the lack of concrete guidance about what this meant in practice and how it could or should be achieved. Evidence suggested that, similar to the primary sample, this gap in translation often went unaddressed. It seems, again like the primary sample, that the main reason these agencies failed to address this lack of operationalisation was the predominance of their agenda for organisational growth which appeared to overshadow concerns for the nature of existing service delivery.

Despite the fact that two of the four secondary agencies (A & B) were probably the largest providers of community-based residential care in Scotland at the time of my involvement, they along with the other two secondary agencies demonstrated a strong commitment to continued expansion. The two smaller agencies (C & D) were characterised by a greater commitment to diversification although they also intended to expand in the variety of areas into which they diversified. These included day care, respite care, supported employment, befriending and services to children. The evidence presented in the next section suggests that both diversification and growth required significant effort at a managerial leadership level to achieve. Where agencies were already very large, it appeared that significant efforts were already being exerted to cope with the complexities inherent in running a large organisation. Whether an agency is either large or getting larger, it seems likely that an agenda for organisational growth, unaccompanied by an

increase in resources (particularly staff) to support this agenda, would detract from the time the agency's leadership has to concern itself with evaluating existing service delivery and grappling with the failure to achieve positive results in particular areas.

The actions and intiatives taken by the agency

Distractions from the quality of direct service being delivered, which were likely to be created by the organisational growth agenda, combined with the tremendous gap in guidance and direction for direct service staff around the task of facilitating community integration, appeared to further manifest itself in some consistent themes which were related to the activities of each agency, and which mirrored those identified in the primary sample.

1. An inadequate programme of training and development for direct service staff which provided little if any knowledge base and practical strategies around facilitating the growth of tenants' relationship networks, nor any opportunity for staff to work through their personal attitudes and concerns about undertaking this work;

2. A pattern of inadequate staffing levels which consistently restricted opportunities for tenants to extend their lifestyles (and consequently, their relationship networks) beyond the world of disability;

3. A failure to recruit or use voluntary effort available from the wider community to facilitate community integration and relationship network development for tenants;

4. A tendency to impose increasing standardisation and responsibility for registration requirements on direct service staff teams, necessitating an increasing portion of staff's time to be used in developing and maintaining complex recording and reporting procedures.

If one combines the lack of clear operationalisation of these agencies' missions to facilitate community integration with a training and development programme for staff which failed to offer a knowledge base or set of practical strategies to build

tenants' relationship networks, the extent to which direct service staff were expected to operate *on a wing and a prayer* becomes clear. Although training and development programmes did exist in each of the four secondary agencies (to a far greater extent than the reader will recall existed in the primary sample), the content of those programmes reflected many issues other than building relationship networks. The implications of creating ever-larger agencies were apparent in some agencies' training and development programmes. In the case of Agency B, it was acknowledged that much of the training and development staff's time was routinely taken up with new project induction rather than extending the competencies of existing staff. In the case of Agency D, the pressures of registration and standardisation came to bear on staff's opportunities for training as financial record-keeping became a training requirement for direct support staff. Most of the agencies did address relationships in a limited way through training, generally by covering the topics of sexuality and relationships with family. Although relevant, these subjects did not directly address the task of assisting tenants to extend their relationship networks, and staff repeatedly cited a lack of training or guidance from supervisors on how to undertake this work as a significant stumbling block to progress.

The problem of inadequate staffing levels went much deeper than simply lacking what might be considered to be an *optimal* scenario. In three of the four secondary projects, it was clear that sufficient staffing did not exist to address the declared mission of the agencies with regard to community integration. For example, where Agency D articulated a philosophical commitment to "full integration" and "tenants having a wide range of satisfying relationships", the support and resources subsequently allocated to tenants were vastly insufficient to begin to address these statements of intent. Interestingly, there was little evidence in any of the four

secondary projects that staffing levels had been reduced from what was originally negotiated in the setting up of the projects, as was the case with the primary sample where the reader will recall that over time, staff were increasingly re-routed to other projects. However, in three of the four secondary projects, grossly inadequate staffing levels resulted in tenants being forced into largely segregated lifestyles with little chance to change this, suggesting that the original negotiations around staffing requirements were based on underestimated need. There was very little evidence of tenants being supported by staff to meet and socialise with others in non-segregated settings or to join community groups. If tenants were able to do this, they either were independent enough to do this on their own or with another tenant, or they were supported by existing family or friends who did not have intellectual disabilities (this was very rare). Tenants typically attended adult training centres, segregated clubs and segregated night classes. Only in Agency C were staffing levels of a quantity to enable tenants to be supported to extend their lifestyles beyond the world of disability and thereby be in situations where the potential to develop new relationships existed.

Many times, in the face of inadequate staffing levels, agencies turned to voluntary effort for support. Three of the four secondary agencys (A, C, D) had volunteers connected to the agency while staff from two of the agencies (B, D) also routinely referred people to local 'befriending' initiatives. Although the sheer lack of available volunteers created a further stumbling block to facilitating wider relationship networks for tenants, where volunteer involvement did exist, it was apparent that, like the primary sample, this involvement was not being engaged in ways designed to promote greater community integration and wider relationship networks for tenants. In Agency A, local volunteers gave their time supporting the livelihood of the organisation (mirroring the traditional relationship volunteers had

with long-stay hospitals), rather than becoming involved with specific tenants on a personal basis. They served on the management committee, fundraised, and augmented inadequate staffing to support tenants on holidays, while the project considered within Agency A had no volunteers involved with individual tenants. In Agency C, the one volunteer who was involved accompanied a tenant to a segregated club every Friday night and otherwise spent time visiting this tenant only occasionally. No introductions to other community members or extended participation in the community had resulted from the involvement of this volunteer. In Agency D, befrienders were used to enable tenants to go out socially but there was no specific emphasis, in these relationships, on connecting people to wider networks through the volunteer. Ultimately, neither the presence of volunteers or staff offered tenants a viable source of support to extend their relationships or their level of community involvement.

Finally, the increasing standardisation that characterised these agencies, combined with the plethora of requirements that local authority registration imposed, created significant distractions for direct support staff from their developmental work with tenants. The effects of standardisation, particularly the workload this created, was most apparent in the large agencies, who operated numbers of projects. Observation of staff meetings revealed just how much time was taken up processing information received from these organisations' head offices, and meeting the requirements to convey complex and varied information back to the administrative centres of the agencies. In Agency B, new 'pro-formas' were constantly introduced by the agency which created increasing paperwork and reporting requirements for staff and project managers to attend to. In Agency C, the smallest of the four secondary agencies, these requirements were noticeably less for the project staff team observed. Members of the team commented that they had a significant amount of autonomy in

defining how they would work and in managing their own affairs. Yet this agency also planned to pursue an organisational growth agenda, and it seemed likely that growth in the organisation would increase the complexity involved in management communicating with individual projects, leading to management implementing greater standardisation and administrative demands on direct service staff teams: a move which, if not accompanied by increased staffing of these teams, would detract from the hours staff had to support tenants on a day-to-day basis.

In addition, all four secondary agencies and their staff teams were affected by registration processes. In much the same way that the requirements imposed by increasing agency standardisation dominated the agendas of staff teams, registration requirements imposed additional tasks of record-keeping and monitoring for staff to attend to within the working week. The job of direct support staff was, it seemed, quickly becoming the implementation of a series of procedures rather than the provision of person-centred, progress-oriented support to individual tenants that many of the agency mission statements referred to.

The activities and actions of the staff team

In considering the four secondary project staff teams, despite the many differences in these groups, there were some striking similarities both between the teams and when comparing each of them to the primary sample staff team. Three particular themes, related to the activities and actions of the teams, recurred consistently and

were significant in the findings from the primary sample as well:

1. The emphasis on maintenance and intra-project relationships (either managing or encouraging these) together revealed a consistent and distinct willingness on the part of staff to assist tenants to maintain (and to a lesser extent develop) relationships with other people who have intellectual disabilities.

2. The dominance of an independence agenda, with the emphasis on supporting tenants to manage the home and develop a repertoire of functional skills.

3. The selective use of persuasion and encouragement, focused largely on functional issues and to a lesser extent on the maintenance of existing relationships, while an attitude of 'waiting to be asked' predominated over offering any form of support for relationship network development outwith the world of disability.

The emphasis on intra-project relationships is in itself a form of maintenance. In the primary sample, the reader will recall that staff were increasingly involved in managing the negative aspects of these relationships as time passed. This was also the case in the secondary projects, most notably in Agency A, where the hostel-type building with satellite flat essentially housed a large number of tenants under one roof. In Agency B, it seems that where tenants were allowed to choose with whom they would live, this resulted in more harmonious relations and less efforts required by staff to compensate for negativity. Yet the overwhelming majority of tenants had little or no say over who they lived with and this showed in the energy staff had to put into managing the often tenuous relationships that resulted.

Beyond managing negative relationships, staff also invested energy in encouraging tenants to develop friendships with each other, and to socialise together. This was particularly true of Agency B, where many of the relationships that existed between this group of tenants, who lived in a series of small flats, were supported and encouraged by staff. In both Agency A and D, where inadequate staffing levels meant staff support to accompany tenants outwith the house was not available, staff also put effort into encouraging tenants to go out socially together in order to offer

support to each other. In addition, in Agency A, there was a strong ethos which emphasised group outings as if (as one staff member put it) "the tenant group were a substitute for a group of extended family, neighbours or friends." Taken together, this variety of efforts around *intra-project* relationships far outweighed efforts to facilitate relationships beyond the projects. Where this did happen, staff were noticeably swayed toward supporting only the maintenance of *existing* relationships (mainly those with other people who had intellectual disabilities and family); and within this, the strongest emphasis was on supporting tenants' relationships with people who also had intellectual disabilities. In Agency D particularly, staff seemed to go to great lengths to encourage such relationships, even when the tenants involved showed little motivation to pursue these relationships. Staff demonstrated a level of comfort with supporting these relationships which they did not appear to share when considering pursuing the development of either new or existing relationships for tenants with people who did not have intellectual disabilities. Sometimes this also included family, and most staff typically allowed relatives to define the expectations that tenants should have of them.

The dominance of an independence agenda, which was both home-based and functional, was by far the most imposing aspect of the four secondary projects observed, and mirrored the primary sample in this regard. No doubt reflecting the job descriptions of the direct support workers, the majority of support given to tenants in the secondary samples was around carrying out household chores or attending to personal care. Yet again, like the primary sample, when staff were questioned about the possibility of this intensive and rote-based form of support enabling tenant to achieve independence at some point, most all acknowledged this was very unlikely. In every secondary project, the percentage of time allocated to things other than this independence agenda was scant, and one staff member in

Project C pointed out that while some time was spent on helping the tenants get out socially, this invariably involved spending time with other people they already knew rather than having opportunities to meet new people.

The importance of this independence agenda was reinforced, like in the primary sample, by the extent to which staff in the four secondary samples used persuasion and encouragement around this agenda. Staff from every one of the secondary projects alluded to the fact that they would assist a tenant to pursue a relationship (referring typically to someone who was a new acquaintance or a member of the network who did not have intellectual disabilities) *if* that tenant *asked* for support. This *waiting to be asked* attitude was certainly not the attitude adopted toward more functional agendas. On functional issues, staff held the view that they would intervene without being asked - in other words, *we will help you because that is what we're here for,* while intervening on relationship network development was viewed more as *we will help if you ask because we're expected to address this* ***if*** *it comes up.*

Evidence suggests there was hardly the same sense of urgency about tenants' social lives that existed around the need to teach tenants skills related to personal hygiene, money management, housework, meal planning, shopping, cooking and health. As was the case with the primary sample, the *let peole do what they want* ethos became something of a red herring used to justify what appeared to be a lack of intentionality on the part of staff in the area of relationships and community integration.

The attitudes and assumptions of the staff team

Three particular attitudes which were identified within the staff team of the primary sample were also consistenly found among the majority of staff in each of the four secondary samples.

1. There were negative assumptions made about the people with intellectual disabilities being supported.

2. There were negative assumptions made about members of the wider community who were either already involved in a limited way in a tenant's life or who were unknown to the tenant.

3. There was a consistent preference for non-involvement on the part of staff which evolved from a variety of assumptions staff held about the implications of their involvement.

As the result of the combined negative assumptions mentioned above, there was a consistently expressed attitude of cynicism about the likelihood that intentional efforts to develop relationships between tenants and the members of the wider community would prove successful. In considering the attitudes that underlay these assumptions, it was difficult to determine whether concluding that someone with an intellectual disability is not likely to be appreciated by members of the wider community is a negative assumption about the intellectually disabled person or the wider community or some combination of both. Having low expectations has historically been an attitude shown toward people with intellectual disabilities; but in this research it seems clear staff from both the primary and the four secondary samples were as likely to have low expectations of community members as they were of those they supported.

Despite the consistency of the views held, staff drew these conclusion it seems, from many different points of reference. For example, in Projects B and D, staff relied

on their experiences of observing tenants having impromptu contact with local community members who they did not know. Staff in Project A relied on their own feelings about spending time with the tenants to conclude that members of the wider community would not respond positively to being introduced to them. Staff in Project C were aware that an initial opposition by neighbours to the opening of their tenant's community house still made them somewhat defensive and reluctant to pursue relationships for tenants with *any* members of the wider community, despite the passage of 3 1/2 years.

Positive evidence of acceptance on the part of community members already having some limited role in tenants' relationship networks seemed to make little difference to staff's attitudes about attempting to develop these relationships further. One vivid example in Project B demonstrated that the primary sample staff team were not alone in seeking support from community members only in times of crisis (the reader will recall this was one of ten themes identified with the primary sample). In this example, the staff member was reluctant to pursue a positive rapport that had developed between the tenant she supported and the local church minister. She did nothing in this regard until agency policy required her to find an independent third party to approve expenditure for this tenant's upcoming holiday. Because it was necessary, the staff member approached the minister and she reported that he happily agreed to become involved. When asked if she thought this positive outcome might encourage her to assist the tenant to pursue this relationship further, this staff member said no: she thought she had "pushed it" far enough.

In Project C, the fact that new neighbours had moved into the neighbourhood and been to the house to introduce themselves, while the neighbour next door had said the tenants were the best neighbours he ever had, did not change the staff team's

position on supporting the tenants to extend their connections with these people. Finally, in Project D, the fact that neighbours asked after a tenant who had gone into hospital, and were appreciative of being able to use the house car park one night when a big concert was on locally, did not make staff feel any more willing or comfortable with the idea of initiating further contact. Instead, as one staff member put it, they generally "kept themselves to themselves", accepting the fact that as a result, they felt quite isolated despite living in a highly populated area. Overall, staff were almost universally cynical about the potential for intentional efforts to develop relationships between those they supported and members of the wider community leading to any positive results. For those who did not express overt cynicism, they expressed apprehension, admitting that they had little experience of operating in an intentional way.

Beyond holding largely negative attitudes about being involved in facilitating relationships in an intentional way, a number of staff from the secondary samples, like those from the primary sample, showed a more fundamental preference for non-involvement, not motivated by cynicism but rather by various beliefs about this being the preferable scenario. In every project, particularly Projects B & D, non-involvement was preferred because of low staffing levels: if a tenant could become involved in something for which they did not require staff support, this was almost always deemed the preferred option. This explained in part why the tenants in Project B and D were repeatedly directed toward segregated activities like segregated social clubs and community education classes. In Project D, tenants were encouraged to go on organised holidays with either the local segregated club or the adult training centre since staff were then not needed to go.

In Project A, staff felt that tenants were demonstrating inappropriate dependence if they wished to have staff support to go out socially or get involved in an organised group or activity. If tenants were reluctant to go alone, they would be encouraged to go with another tenant and be discouraged from expecting staff support. In Project C, while staff assisted tenants to become involved in integrated activities, they withdrew from offering support largely because they felt they were interfering by their presence. In the case of one tenant, a year into an integrated exercise club, she had not managed to make the acquaintance of any of the ladies who also attended, despite these women responding positively to her being in the class initially. For many months, staff had opted to 'wait outside' while the class went on, so they knew nothing of why this tenant had not gotten to know anyone. Overall, despite a mixture of viewpoints, there was consistency among staff from the four secondary projects about the value of non-involvement and this mirrored the position taken by staff in the primary sample.

but rather appeared insufficient to draw any firm conclusion from. It was thought that this lack of evidence was probably the result of the much shorter period of investigation used with the secondary samples.

In terms of the themes around the primary sample staff team, there was nearly a complete refutation of one theme: *the tendency to focus on the needs and preferences of staff.* Except for Project D, which openly discussed the need to plan tenant holidays around staff holidays (something that other staff teams may well have done, but of which I had no direct evidence), there was not nearly the range of evidence, demonstrating staff consistently putting themselves before tenants, as that which existed for the primary sample. Only one other theme related to the primary sample staff team was not supported by the evidence from the secondary samples: *a tendency to react to volunteers' presence by reducing effort.* In the case of this theme, there was not enough evidence to either confirm or refute the validity of this theme.

In Figure Eighteen, the extent of confirmation or refutation that resulted from considering the four secondary samples, in light of the entire group of themes developed from the findings of the primary sample, is documented. Before moving on to consider how these results impacted upon the validity of the provisional explanatory framework developed around the primary sample and introduced at the end of Chapter Eight, consideration must first be given to possibility that there were either useful elaborations of the original themes that came to light, or different themes, not identified in the primary sample, that arose in considering the secondary samples. I turn to these questions now before ultimately considering the generalisability of the explanatory framework.

Figure Eighteen: Support for Conclusions drawn from Primary Sample

Results of evidence from secondary samples	Agency Philosophy/Mission	Agency Actions/Initiatives	Staff Team Activities/Actions	Staff Team Attitudes/Assumptions
STRONG SUPPORT	1. A failure to operationalise the declared mission and philosophy around relationships and community integration. 2. Inadequate content and emphasis on relationships and community integration in direct support staff's job descriptions. 3. A commitment to an organisational growth	1. An inadequate programme of training and development for for direct service staff. 2. Inadequate staffing levels. 3. A failure to recruit or use voluntary effort available to facilitate community integration and relationship network development. 4. A tendency to impose increasing standardisation on direct service staff teams.	1. An emphasis on maintenance rather than development. 2. Emphasising the promotion of home-life and functional independence agendas. 3. A tendency to selectively use persuasion and encouragement. 4. Seeking support from community members only in times of crisis.	1. A tendency to make negative assumptions about the people with intellectual disabilities being supported. 2. A tendency to make negative assumptions about members of the wider community. 3. A preference for non-involvement.
LIMITED SUPPORT	1. A focus on physical presence rather than social relationships. 2. A more strongly articulated mission to develop housing than to develop support.	1. A failure to articulate Priorities for support.	1. Planning or supporting opportunities to participate without consideration for for relationship potential. 2. A tendency to disregard the the importance of individuality in extending the relationship networks of tenants.	1. A tendency toward rose-coloured glasses. 2. Being unwilling or unable (due to agency policy) to leave a tenant at home alone.
REFUTATION			1. A tendency to focus on the needs and preferences of staff.	
NOT ENOUGH EVIDENCE TO DETERMINE		1. The tendency to problem-solve on unrelated issues without consideration for the impact on tenants' relationships.	1. A tendency to react to volunteers' presence by reducing effort.	

Elaboration on the primary sample's findings

Where some findings from the secondary samples supported the themes identified in the primary sample, they also offered more information about how a particular theme might manifest itself in practice. For example, although already mentioned in the context of the *emphasis on maintenance* theme, the focus on intra-project relationships that staff typically adopted became much more obvious in considering the secondary samples than it had in the primary sample. The fact, revealed by the secondary samples, that focusing on intra-project relationships involved both mediating negative relationships and encouraging positive relationships demonstrated clearly the extent of effort staff were actually putting into relationships which were neither new nor beyond the world of disability.

In addition, although it was clear that cynicism about the results of intentionality was a theme which characterised the attitudes of the majority of staff interviewed, the secondary samples suggested that this may be more than cynicism over the perceived *unwillingness* of community members. Staff from Project B & C also expressed a *distrust* of members of the wider community, adopting a protectionist attitude toward the tenants whom they saw as vulnerable. One staff member from Project B noted that if a local acquaintance of the tenant she supported took a greater interest in him, she would wonder "what his angle was". While in Project C, the protectionist emphasis in the direct service staff job description (as well as some parts of the agency mission statement) had obviously been internalised by staff, causing them to adopt a cautious and guardian-like approach to supporting tenants around developing relationships. Interestingly, it also became clear that staff struggled harder and more often with the essentially positive but patronising attitudes expressed by community members, than they did with the overtly rejecting

attitudes. This suggested that highly skilled and well thought out responses to these kinds of attitudes need to be developed to shape them in ways that would bring positive outcomes for tenants. In Project C particularly, staff struggled with this and were apt to dismiss the potential that may have existed in community members who demonstrated a patronising approach.

Further, in Project D, it became clear that if the competing agendas facing staff were strong enough, while staffing levels remained at a minimum, this would cause staff to abandon altogether their role in facilitating new relationship development for those they supported. Evidence from Project D suggests clearly that staff did little if anything to facilitate new relationships, other than referring tenants to befriending services and calling on adult training centres or social workers to do this kind of work. The staff seemed to be coming experientially to the conclusion that this was no longer part of their job which meant in practice, they could *wash their hands* of this agenda.

Finally, the implications of tenants' largely compartmentalised lifestyles became more evident in the secondary samples, as staff showed a significant lack of knowledge about a number of aspects of tenants' relationship networks. For example, in Project B, one staff member was largely unaware (prior to the interviews with myself) of just how tenuous one tenant's relationship network was, and how one event could bring many of the positive aspects of the network to an end. In Project D, staff lacked knowledge of one tenant's important relationships when she was in other places, like the adult training centre or staying with family. As a result they could neither support the development of these relationships, nor in one instance, locate her when she did not return home one evening. These examples demonstrated that staff were almost as unprepared to adequately support the

maintenance of tenants' relationship networks as they were to support the development of these networks.

The addition of new themes that evolved from the secondary samples

Two interrelated themes evolved from considering Agencies A and B, which did not come to light in considering the primary agency. First, because these agencies functioned as housing associations, the accommodations they provided to people with intellectual disabilities were purpose-built through capital building initiatives. This contrasted both the primary sample and secondary samples C and D, which leased ordinary houses and flats as community-based accommodation for those they served. It became clear from this contrast that the nature of the physical project model adopted was likely to have implications for both staff and tenants in relation to community integration.

The purpose-built housing model was typically large, detached from other residential property in a particular community, and located on the outskirts of a community. Such a scenario had significant implications for the extent to which members of the local community, particularly neighbours, viewed the tenants' residences as 'special' and this was demonstrated by the noticeably limited contact tenants in both Projects A and B had with local neighbours. In addition, the size of the project established a 'ready-made social circle' for tenants and staff, where 'the neighbourhood' became the project. This seemed to encourage staff to make greater efforts in the area of intra-project relationships, and consequently caused them to adopt an attitude of complacency toward extending tenants' social lives beyond the project. Whereas in contrast, the individual group homes in Projects C and D were

faced with feeling isolated if they did not make efforts to extend tenants' social contact and involvement beyond the project. Finally, the location of the purpose-built projects often meant tenants could access very little in terms of social amenities or groups locally, thereby making the inadequate levels of staffing a critical factor which often compounded the 'project as community' culture since tenants' opportunities to go beyond this were severely limited.

In general, the elaborations and additions to the range of themes identified through the primary sample revealed useful additional information that furthered this researcher's understanding of the dilemmas facing agencies and staff in supporting relationship network development and community integration for the intellectually disabled people they serve. How the overall picture created by the secondary samples concurs with the provisional explanatory framework derived from the primary sample is the subject of the final section of this chapter.

Implications for the initial explanatory framework

For the most part, and as demonstrated by Figure Eighteen, the findings from the secondary samples give credence to the explanatory framework created around the primary sample. The discrete themes, which were confirmed by the evidence from the secondary samples, included themes associated with each of the three unifying themes - competing agendas, complacency and resistance - which underpin the provisional explanatory framework. Meanwhile, the first part of this chapter demonstrated that the poor relationship network and community integration outcomes for tenants in the secondary samples were consistent with the primary

sample. Therefore, it seems likely, given the degree of congruity in the findings generally, that the same vicious circle, which was shown to exist for the primary sample, also existed in each of the secondary samples. However, the question of generalisability does not end with that. There were elaborations of, and additions to, some themes, and even a refutation of one theme from the original explanatory framework. These must be considered in order to fully address the question of generalisability.

In terms of agency themes, the fundamental impact that the project models adopted by Agency A & B seemed to have on influencing community integration outcomes requires this contributing factor to be added to the existing explanatory framework. In addition, the refutation of staff's tendency to focus on the needs and preferences of themselves proved most interesting to consider in light of the evidence of generalisability. Given that there was very little evidence from the secondary samples of staff adopting this focus, it seems the presence of this in the primary sample indicated this theme was likely to be peculiar to a staff team working without adequate leadership: a situation which existed in the primary sample for much of the time I was involved. It seems one could expect the absence of leadership would not be a typical scenario, and therefore this aspect of the provisional explanatory framework would not be generalisable. However, I found it interesting to note that although the secondary sample staff teams did not demonstrate this tendency, in my observation they also did not demonstrate the positive attributes associated with the primary sample staff team which were discussed in the final section of Chapter Eight. One explanation for this may be that the length of my involvement with these samples was not sufficient for me to observe these positive attributes. Another possible interpretation may be that what is generalisable in this interesting pattern of evidence is nothing more than, as

concluded above, the need for leadership. Although the simple presence of leadership may not be able to affect the personal attitudes of resistance that staff may hold about using intentionality in relationship development, it may be able to *prevent* staff who hold some baseline of positive values about the rights of people with intellectual disabilities from becoming their own worst enemy. If staff are not, at a very rudimentary level, prevented from falling into the trap of doing their job in a way that is tailored to their needs, rather than the needs of those they support, there would be no basis upon which staff could embrace a commitment to offering - not just tenant-centred support - but proactive tenant-centred support, particularly in the areas of relationship network development and community integration. The secondary projects appeared to demonstrate leadership on this level was in place.

Beyond these issues, the scope for generalisation was also expanded by the findings from the secondary samples. The evidence of all five agencies adopting a commitment to organisational growth, despite the size or age of each organisation, brought to light the fact that the explanatory framework was not simply a framework applicable to young and relatively small organisations (as the primary sample agency was when I became involved). In a sense, this realisation extends the degree of generalisability farther than one might have expected, highlighting the fact that, although there were a variety of agencies considered, there were no exceptions to this growth mentality.

Finally, the emphasis on supporting tenants in relationships or participation with other people who also have intellectual disabilities, which proved generalisable to all the projects considered, raises a critical realisation: that people with intellectual disabilities, who are supposedly avoiding (or putting behind them) the tragedy of enforced segregation, are largely being supported to continue to live in a world of

disability. They are therefore *in* the community but not yet *of* it. (Schwartz, 1993) The debate over whether there is the potential for care *in* the community to become care *by* the community can hardly be adequately considered - particularly the potential of ordinary communities to 'care' - until a number of priorities and assumptions about supporting people with intellectual disabilities, which are currently held by residential agencies and their staff, change. How these priorities and assumptions should change, given the findings of this study, is the subject of the final chapter of this thesis.

CHAPTER TEN

"The Way Forward"

Introduction

In reflecting on my experience of conducting this research, and the responses of those I interviewed, it seems the complexity of the dilemmas surrounding the facilitation of community integration may often cause people to recoil from trying to find positive ways forward. Chapter Three illustrated the complexity of the subject, and the variety of perspectives which have been taken by other authors. In an attempt to avoid being overcome by the sheer complication of the perceived problems, I chose to focus this study on the role of staff for two reasons. I chose this focus first, because this avoided 'blaming the victim': (attributing the source of the problems to people with intellectual disabilities themselves without first determining that other involved parties did not have a role to play; and second, because it would be within this area, that a professional or organisational commitment to change, in response to disappointing research findings, could have the most influence. Although this chapter does not allow adequate space to reflect on all of the issues raised within this thesis, I have addressed those issues which I think are the fundamental starting points for moving forward from the findings which have been generated.

Putting the study's findings into perspective

This study has been, like the body of literature that preceded it, convincing in its documentation of the extent to which people with intellectual disabilities have not experienced significant levels of community integration. For a long time however, researchers and theorists have been writing about the need to focus the attention of agencies and staff teams on improving these outcomes. In 1985, Walker commented:

> ...we must increase our awareness of the limited dimensions of social networks for many people with disabilities and place emphasis on the expansion of these dimensions. (p. 190)

Still however, this study suggests quite strongly that agencies and staff teams continue to give severely limited attention to this issue and thereby fail to recognise their culpability in maintaining the status quo for those they support. In Chapter Seven, I described the need to keep a record of the distribution of paracetemol as a *detail* in the overall support of people with intellectual disabilities which was clearly attributed great *significance*, as evidenced by the record-keeping procedures staff were required to follow in this regard. In contrast, when one staff member from the primary sample described a holiday camp co-ordinator's decision to bring with her, the friends Gary had made in the previous year, when she collected him from the train, as "such attention to *detail*," the sense of surprise that underlay this comment belied the *insignificance* staff associated with supporting relationships. It seems that at the crux of this entire thesis is the need to reconsider what details are significant: in other words, *what is important to focus upon in supporting people with intellectual disabilities?*

A gut reaction to this question, and no doubt one initially difficult to dispute, would be that every staff function described in this thesis is important. Yet when faced with the limited time, both of staff and those being supported, the question of what is important becomes more a question of priority-setting. For in choosing one thing to focus on, it must be accepted that something else is given up or put aside. The evidence in this study suggests that the main priority in community residential services today, is still as Alan Tyne described in 1987:

> There were limited and narrow views of what constituted 'development and growth' in people's lives, with often inappropriate attention to limited 'skills programmes.' (p. 89)

Given that very little appears to have changed in the last decade, and the emphasis within staff support on promoting functional independence continues to dominate, there seems little question as to why both community integration and relationship network development for those being supported has been so poor. Understanding the basis upon which the predominant emphasis on functional independence has evolved is an important first step in beginning to recognise how these community integration outcomes can be improved.

The background to a focus on functional independence

The reader will recall the arguments raised in Chapters One and Two which demonstrate that both the decision to open institutions, and the subsequent decision to close these same institutions, were motivated by optimism about the potential of people with intellectual disabilities to be trained and to improve functionally. Indeed, the deinstitutionalisation movement sprung up after early optimistic attitudes about the potential for intellectually disabled people to increase their level

of competence in institutions were replaced by strong cynicism that suggested people with intellectual disabilities could not learn, but should be kept in institutions to avoid them becoming a drain on society. Meanwhile, policy documents made only limited reference (particularly in Scotland) to community integration and the importance of relationships developing between people with intellectual disabilities and members of the wider community. In addition, the reader will recall that in Seebohm's Report (Home Office, 1968), the emphasis was on *the integration of services*, not the integration of service recipients. The common denominators in this history was a focus on how to maximise the functional competence of people with intellectual disabilities, and this was the primary rationalisation by which early political support for community care was mobilised. Of course, the scandals of institutions, which were revealed by both the press and researchers, sparked public outrage that clearly influenced politicians. Yet it seems abundantly clear that the politicians and professionals *who supported moves to community care*, did so not only because they acknowledged the institutional model was largely inhumane, but also because they *expected* people with intellectual disabilities to develop increased competencies as the result of living in the community.

This pattern of events offers a plausible explanation of how the functional independence agenda came to dominate the support offered to people with intellectual disabilities through community care. In retrospect, it is clear that adopting a new emphasis on community integration and relationship network development will require service providers and staff to re-think a number of assumptions they currently hold about what is important in supporting people with intellectual disabilities. In particular, they would need to consider what evidence may exist which demonstrates that pursuing a predominant emphasis on functional independence is no longer a valid stance.

Reconsidering the functional independence agenda

Perhaps it may be too cliched to say the writing has been on the wall for some time about the need to reconsider the goal of functional independence. No doubt for many professionals, who believed that people with intellectual disabilities would make great strides in functional competence as the result of moving out of institutions, the comments made in a report by the Social Services Committee of the House of Commons in 1985 would prove hard to accept. Yet they are perhaps more relevant today than ever.

> While the disabilities of long-stay patients may well be heightened by institutional care, the simple facts are that there is little prospect of major change for the better for many mentally disabled people... many people need long-term care, wherever and by whomever it is provided, because of their intrinsic disabilities... (HMSO, 1985, para 25)

In general, this report concluded that while people with intellectual disabilities made strides in functional competence as the result of relocation, a sustained development in this it seems, had not typically followed. In 1994, these findings were re-confirmed by Emerson & Hatton (1994). The comments made by staff interviewed for this study, about the lack of potential for those they supported to become fully independent or to achieve a significantly greater level of independence than they already had, demonstrated still further the somewhat questionable pursuit of functional independence as the main theme around which support is currently provided.

In addition, the idea of working toward such forms of independence have been criticised in recent social work texts. According to Compton and Galaway (1994):

> The notion that we should never do anything for people that they can do for themselves seems to us to be very destructive of the nurturing relationships that are necessary between human beings. We are socially interdependent beings, not totally independent ones. What better way to express concern for another man than to help in a concrete, easily understood way by offering to relieve him or her of a dreaded task? The condition of total independence without the ability to take from others or the impulse to give to them is pathological. (p. 463)

This quote makes clear the connection between pursuing independence and undermining relationships. In some ways, this reality is no surprise and one does not have to look hard across contemporary literature to find this theme recounted in other genres. For example, the novel *Independent People*, written by Icelandic author, Halldor Laxness, who won the Nobel Prize in 1955 for it, was just reprinted by Random House in 1997 and is described as "a moving yet unsentimental portrayal of a man isolated by independence."[1] Likewise, the American best-seller, *Habits of the Heart* (Bellah, et al. 1995), describes a powerful sociological study of contemporary American society, which reflects the growing social implications resulting from the quest for independence and individualism.

Many would say such references to pursuing functional independence are irrelevant to people with intellectual disabilities, precisely because achieving this level of functional independence is so unlikely. Yet adopting this stance does not then seem to trigger a critical questioning of the validity of pursuing this as the priority for support. More critically, I found evidence, of the pathology referred to in the above quotation, in the interviews I conducted with the intellectually disabled people

involved in this study.

> I don't get help from my flatmate. I do it all myself and he does it all himself. If he asked me for help, I'd say no....And Catriona wouldn't ask for help from me, she'd say no, I'll do it myself. ...I don't ask Ralph for help. He couldn't help me because he (isn't allowed) into my room. I can't go in his room either.

In addition to these examples, the majority of staff in this study were of the general opinion that people with intellectual disabilities were less sensitive to the feelings of others than people without intellectual disabilities. It seems that both in emphasising the value of functional independence and in thereby failing to emphasise the importance of social interdependence, the support typically provided to people with intellectual disabilities has undermined their willingness and ability to engage others in ways which engender friendship. Michael Bayley's latest book, published at the time of writing this chapter, focuses on strategies to encourage the relationships of people with intellectual disabilities and draws similar conclusions. Bayley argues that "there should not be an uncritical assumption that our goal should be maximum independence." (1997, p. 105)

Beyond the importance of critically debating existing priorities, this study also demonstrates that the most significant consequence of pursuing the functional independence agenda has been the tendency toward complacency that direct support staff consistently exhibited with regard to pursuing relationship network development and community integration. Making a philosophical shift from what has become an almost tireless focus on functional independence requires what Compton and Galaway (1994) describe as "learning how to assess the sources available to (people) for meeting dependency needs" rather than simply trying to eliminate dependency. (p. 463) This involves reconsidering the meaning of independence, as it relates to dependence.

Reconsidering the meaning of independence

The importance of independence as a concept in the field of disability has largely been focused upon the need to minimise or avoid dependency. In contrast, the independent living movement, and similarly the supported living movement, have for some time defined independence, not as being capable of managing life without assistance, but as "choosing and living one's own lifestyle - regardless of the amount and type of support necessary." (de Jong, 1983) This definition highlights the importance of minimising the imposition of control, rather than the provision of assistance, by others. For people with intellectual disabilities, the extent to which they are able to exercise control over their lives has been hampered not only by the unwillingness of others to allow this, but also by the cognitive and experiential deficits that these individuals typically face. Therefore, an additional aspect must be added to this definition of independence, to enhance its potential to minimise harmful dependency.

The reader will recall from Chapter Three that Morris (1993) has emphasised the fact that having either largely professionally-dominated sources of care, or a single informal carer, are both unsatisfactory options for people with disabilities. Similarly, I would argue that in the case of people with intellectual disabilities particularly, where taking control necessarily involves gaining support to do this, *the diversity and number* of sources of support is the most critical factor in preventing support from becoming control. In terms of promoting independence then, a re-defined mission might most helpfully be:

> **...to assist people with intellectual disabilities to choose and live their own lifestyles, as far as possible, by assisting them to expand the range and number of sources of support through which they can meet their dependency needs.**

Although not abandoning the importance of minimising dependency, such a definition re-orients services away from the focus on a functional *'do it alone'* independence agenda to a social *'do it with assistance'* interdependence agenda. Adopting this new perspective on independence thereby prioritises the need to extend people's relationship networks and sources of security, as was clearly not the case with the various projects considered in this study. Bayley concurs on the importance of this reorientation, saying:

> ...the basic need is for service systems in which relationships are seen as central and there are appropriate structures to support them...If community living is to be more than a political slogan, we must find means of honouring, encouraging, and supporting relationships which make people alive. (1997, p. 101)

Reconsidering the emphasis on maintenance

Beyond the need to reconsider and reconceptualise the focus on functional independence, staff's emphasis on maintaining relationship networks, primarily the disability-aspect of these, reflects a similar theme for change. The argument presented above, for moving beyond the promotion of functional independence, at least in part, in response to the fact that the gains related to relocation have been shown not to accrue at nearly the same rate in the longer-term, is really evidence of a broader need *to develop new objectives for the period beyond relocation and transition.* This need, it seems, also applies when considering the emphasis on maintenance which this study demonstrated. The origin of this emphasis was, it seems, largely related to concerns surrounding relocation, where the importance of assisting people to maintain contact with those with whom they lived prior to their move, was stressed. As time passed however, it seems both the evidence from this study and common-sense suggest these relationships may not remain as critical to

maintain, except of course as a reaction to the lack of new relationships that people have to take their place. With a focus on expanding people's networks, a greater balance between maintaining old relationships and pursuing new ones can be struck, which is more reflective of the passage of time since relocation than the dominant emphasis on maintenance evidenced in this study has been.

In addition to de-emphasising the focus on maintenance for this reason, a revised commitment to independence which stresses *expanding the range and number of sources of support by which people with intellectual disabilities can meet their dependency needs* requires an assessment of the extent to which existing networks offer, or could potentially offer, a way for people to meet some of their dependency needs. This involves reflecting on the quality of these relationships, which the evidence in this study showed was not typically good, particularly among those relationships involving other people with intellectual disabilities. While 97% of direct support staff involved in this study felt people with intellectual disabilities should not be forced to live with people they do not like, the reality is that many did. In addition, it was clear that those they lived with were not readily able to assist with meeting their fellow tenants' dependency needs. Its ironic that while some debate the capacity of people with intellectual disabilities to develop, participate in, and maintain positive relationships, we routinely expect them to cope with the most challenging of interpersonal situations: living with people with whom they do not get along and whom may be able to offer only very little instrumental support. For most people without intellectual disabilities, it is unlikely they could imagine a more unacceptable and indeed socially challenging scenario than this one.

In this research study, the emphasis on functional independence and on maintenance were the two critical themes related to staff activities which required fundamental

reconsideration if the strength of competing agendas to community integration and relationship network development was to be diminished. No staff team however, could be expected to achieve such significant changes in priorities and ways of working without the leadership and support of the sponsoring agency.

The need for change at an organisational level

In order to support such a shift in emphasis among direct service staff, this study demonstrates that sponsoring agencies would first be likely to have to discard their own primary competing agenda: the commitment to organisational growth. One can begin to understand why this growth agenda needs to be critically reconsidered by applying corporate principles to these human service agencies.

In the corporate world, periods of growth are typically associated with confidence about the quality of existing production or service delivery. Whether growth involves new (different) ventures, or the expansion of existing ventures, the decision to grow is calculated very carefully, during a period of consolidation in which the health of the existing organisation is evaluated. Within the world of Scottish community care, or at least the five agencies considered in this study, it seems there was little evidence of this pattern of consolidation and growth being undertaken by provider agencies. Instead, it seems these agencies were committing themselves to growth agendas, both without the excess of resources (particularly human resources) to do this, and without first considering whether the quality of their current provision was sufficient enough to warrant a redirection of effort toward expansion activities. In this study, the disturbing degree to which agencies' mission statements related to community integration and relationship network development were not

operationalised or supported largely went unacknowledged and unaddressed, while growth, often based on the same model of service, was pursued.

Where recent community care policy has called for a *marketplace* of small providers, in lieu of a few very large ones, evidence in this study consistently suggested that agencies were caught in a continuous cycle of growth. In retrospect, without additional resources available to direct service staff teams within these agencies, to meet the bureaucratic requirements of increasing standardisation which appeared to consistently result from organisational growth, it seems staff will continue to have little chance of addressing more tenant-centred issues, particularly the *development* of their effectiveness in areas, like community integration, where outcomes for tenants are currently disappointing and there is an acknowledgement that adequate effort has not been put into correcting this.

Adopting a positive emphasis on community integration

Even if the agenda for organisational growth were put aside or fully resourced (although even properly resourced growth may still be detrimental to the quality of support offered to tenants), agencies would have to do more than this if they wished to address the atmosphere of complacency, with regard to the promotion of community integration and relationship network development, which this study demonstrates existed at a direct service level. Most fundamentally, agencies would have to formally adopt a community integration agenda which would be fully operationalised at a number of levels. This would include mission statements that are detailed and specific about the nature of support the agency intends to offer. Within these statements, agencies would need to establish certain agendas as explicit

priorities, rather than allowing priorities to evolve idiosyncratically from practice, either as the result of old mentalities of care being carried over, or from a tendency to define intentions by what existing resources will allow.

Inherent in prioritising a community integration agenda would also be the need to review the content and focus of direct service staff's job descriptions and recruitment procedures for these positions. The care and protection emphasis, which is typical in existing job descriptions, would have to be countered by an equal if not greater emphasis on assisting tenants to build positive relationship networks that can increase both their feelings of security and belonging, and lessen their dependence on the paid staff team. Recruitment procedures would emphasise finding staff who were themselves locally involved, as well as committed to using their own personal connections to facilitate the integration of those they would be hired to support.

Critically, the programme of training and development would need to provide direct service staff with an adequate knowledge of practical strategies for facilitating community integration through relationship network development. According to Felce and Toogood (1988):

> It is important to acknowledge the considerable complexity of the issues which staff attempt to address in their daily work. Staff working in the community need an incredible range of skills...As our aspirations of what can be achieved have grown, so have our expectations of what staff must achieve. (p. 187-89)

Staff interviewed in this study consistently reported the lack of training, particularly that focused on extending tenants' relationship networks. As well, staff in the primary sample reported either a lack of supervision or a supervisor who herself did not have knowledge or experience of strategies to facilitate relationship

development and community integration. This finding demonstrates the importance of both training middle managers in this area, and where possible, recruiting middle managers who have existing knowledge or experience in addressing community integration on a practical level. It is not enough to train direct service staff alone. Indeed at every level of the agency, staff should understand how a philosophical commitment to community integration can be operationalised in practice, so they can contribute to this process (for example, by sharing their own connections) and develop an optimistic attitude toward the potential of such efforts to yield positive results for tenants. Where ten years ago, it may well have been argued that the resources to build an adequate knowledge base and training programme did not yet exist, this is no longer the case as a range of literature and practical resources have been developed internationally to address this subject.[2] Perhaps the only warning in this regard is that training and development, used as a 'fix-it' approach by an agency which resists formally adopting community integration as a guiding principle for every aspect of its work, will no doubt fail, and leave staff with justification to adopt an even greater level of resistance than was demonstrated to exist in this study.

Beyond the issues surrounding the size of an agency raised in the previous section, the size and type of project must also be reconsidered. In both secondary samples where a large, purpose-built project was typical, the failure to use ordinary housing, and the decision to group large numbers of people with intellectual disabilities together which underlay this project model, appeared to significantly impede staff's motivation to work on the development of tenants' relationship networks beyond the project. It seems that housing associations serving people with intellectual disabilities face a fundamental challenge to their existing mission if they are to adopt a commitment to prioritising a community integration agenda. Yet at the

same time, these agencies' scope for becoming integrated housing providers, and thereby being in a position to intentionally facilitate supportive housing communities (like the integrated co-operatives which have proven successful in the United States[3]) is much greater than for agencies which don't have a mechanism or remit to create housing as well as provide support. Of course, the tensions which have typically arose where people with intellectual disabilities have been provided with housing and support by the same agency, must be rectified.[4] For example, it was clear in the two housing associations considered, that people could not remain in their homes if their support needs changed. Setting up more individualised support arrangements seems to represent the only way forward for resolving these dilemmas. And indeed one reaches a similar conclusion when considering the shortcomings of the group home model, even where this involves the use of ordinary housing. The group homes in this study were not without their own drawbacks, particularly the relationship tensions which developed because tenants were expected to live with people with whom they did not get along. Clearly, this is an issue that needs to be addressed by all residential provider agencies in the future.

All agencies could also pay greater attention to weighing up the strengths and weaknesses, related to facilitating community integration, of particular geographic communities or neighbourhoods, when they are in the process of selecting appropriate housing. What would perhaps be most useful would be the creation of an inventory, which would allow staff to rank various communities or neighbourhoods for their likelihood to facilitate community involvement and inclusion of tenants who might live in these areas. In undertaking this work, it must be recognised that these issues extend far beyond simple questions about the availability of public transport and the presence of local amenities.

Finally, agencies should undertake specific initiatives designed to encourage community involvement. These may not be new initiatives, but rather an altered version of what they currently do. For example, agencies could continue to recruit volunteers, but rather than doing so on the basis that they are committing themselves to sustaining the organisation or simply developing one-to-one relationships with tenants centred around pursuing some activity, volunteers could be recruited to focus on connecting tenants to *the people* in their local communities. The fact that staff interviewed in this study so often had never considered volunteers could have a role in assisting tenants to extend their networks suggests that such an emphasis was neither being identified nor supported at an organisational level. In addition to altering existing initiatives like befriending and volunteering, there is also a need to expand the ways in which ordinary community members can become involved with people who have intellectual disabilities. Befriending and volunteering are not the only solutions, yet service providers appear to show little commitment to innovation in this area.

In addition however, reconsideration would need to be given to the processes used to recruit volunteers. Evidence from this study suggests that volunteers were often put under more scrutiny, and asked to jump through more hoops, before being *allowed* to become involved with tenants than newly recruited staff were subjected to. Such steps, no doubt adopted to prevent potential abuse, were obviously out-of-balance with other preventative measures and resulted in the potential informality of support being overly professionalised. The presence of this process also precluded ordinary relationships from developing naturally, where people who showed an interest in a tenant were often directed to the volunteer co-ordinator (primary sample) or asked to accept a contract and job description (secondary sample C). Better and less invasive methods for evaluating people's intent and

ability to befriend someone with an intellectual disability need to be devised, with the risk inherent in these relationships, as with any relationships, acknowledged and accepted on the same basis that other forms of risk-taking are supported.

The variety of suggestions for organisational change made above involve mainly reorientation or redirection of existing efforts and resources. The question of resource implications must not however, go unaddressed.

Addressing the resource implications of change

Although changing the way things are already done could go a long way to supporting a philosophical commitment to the importance of a community integration agenda, it seems some specific resource implications would also arise in undertaking such a mission. In particular, this study revealed that the staffing levels in some projects were clearly insufficient (even with a change in emphasis) to support tenants to extend either their relationship networks or their involvement in the local community. These inadequate staffing levels only reinforced both the attitudes of complacency staff typically held and the extent to which they felt their only option was to encourage the continuation of tenants' involvement in the world of disability. However, as confirmed by some staff interviewed, adding staff who would simply do 'more of the same' would not be likely to improve community integration outcomes. Only once the competing agendas and complacency were addressed could the injection of more staff make a real difference in this area.

Overall, the most significant resource implications would however be likely to evolve from efforts to offer tenants more integrated and personalised living

opportunities. Accepting that existing project models are incongruent with the promotion of community integration would require a philosophical commitment to change that would justify the expenditure necessary to reformulate these projects. In this study, only secondary Agency C articulated a commitment to enabling tenants who lived in group homes to move on to more personalised living opportunities. The other agencies appeared, through their business plans and the evidence of new projects getting underway, to remain committed to the same models of housing as had been developed previously.

In retrospect, making the philosophical leap toward recognising the importance of community integration, and doing so to the extent necessary to adopt an organisational commitment to changing the current models of housing, requires people at all levels of an organisation to have acknowledged two important realities demonstrated by this study. First, they must recognise the extent to which they have resisted believing that community integration in any significant sense is possible for tenants; and second, they must recognise that the extent of their resistance has not been based on having seriously tried and failed in this regard, but rather on an apprehensiveness which needs to be overcome so that the real potential for community integration can be explored. What McConkey (1987) referred to as "untested presumptions" and what I refer to as "disintegrating assumptions" cannot perhaps be any better illustrated than in this example.

Recognising and tackling underlying resistance

It has been said that optimism in this age is nothing short of a revolutionary act.[5] The explanatory framework generated through this research demonstrates the extent

to which attitudes of resistance toward facilitating relationship development for tenants fundamentally contributed to sustaining the vicious circle which was shown to exist. The evidence which underpinned the framework also suggested however, that this resistance was often likely to be concealed by attention to competing agendas, and the complacency toward working on relationship development which evolved as a result. This is a complicated reality which nonetheless must be dealt with by organisations committing themselves to the primacy of a community integration agenda.

As suggested earlier, the recruitment and induction of staff, on the basis that their role is fundamentally concerned with facilitating the development of meaningful relationship networks and community involvement for tenants, would hopefully avoid in future, the *reactive* resistance to this agenda which staff in this study appeared to demonstrate in interviews. This is not to suggest that all staff would not share *some* sense of apprehension about this work; but properly recruited staff, exposed to a well-developed and grounded programme of training, made aware of the availability of competent supervisory support, and given the opportunity to work through personal reservations in order to develop a sense of team commitment to the task, are likely to demonstrate significantly less resistance than the staff who participated in this study. Such an approach to inducting direct support staff would of course, then need to be followed by on-going opportunities for developing skills and knowledge, sharing experiences and ideas in staff meetings, and accessing supervisory support.

In dealing with the resistance likely to be encountered among *existing* staff, the challenge to turn this into positive energy becomes much greater. It seems that the way in which an agency approaches adopting a community integration agenda as the

new priority agenda will influence the level of resistance staff may express. Three suggestions appear important to make. First, its likely that securing the support of others involved in the agency would be necessary before the agenda was formally introduced to existing direct service staff. This would minimise the extent to which direct services staff might view the priority change as *optional* and therefore, able to be resisted. Securing agency-wide support would need to begin with the management committee, for without this group understanding and supporting the shift in priorities, it seems unlikely the agency could fully embrace the change. Second, it would be important for the agency to admit and take responsibility for failing to prepare and support staff to pursue this agenda effectively in the past. Interestingly, 83% of the staff from the primary sample and 54% of staff from the four secondary samples felt their supporting agency *did not* admit when it failed to achieve what it intended to achieve. It seems important for staff morale that supporting agencies are open to admitting past inadequacies, while able to convey that they want to work in partnership with direct service staff to change this in the future. Thirdly, assurances about a programme of training and adequate supervisory support being available need to be given to existing direct service staff and then delivered on. In the end, it is important that these staff and their managers do not feel *less competent* to carry out their roles than newly recruited personnel. Finally, realistic expectations about success in building relationship networks and community integration for tenants should be conveyed to staff. Such work may not always bring great rewards; but, given the evidence in this study, its likely staff would acknowledge that focusing on enhancing the functional competence of tenants no longer produces the amount of rewards it once did.

Supportive changes required at a wider level

Three critical changes are required at policy and systems levels in order to support community residential care agencies and staff teams to prioritise community integration agendas.

First, the purpose and practices of registration & inspection units needs to be reconsidered. Evidence from this study suggests that the methods by which premises are inspected, and registration is awarded, are almost wholly documentation-driven. The underlying assumption appears to be that a certain amount and type of documentation, provided by an agency and staff team who supports a group of tenants, can be considered an accurate depiction of the day-to-day reality of these people's lives. Such an assumption, while very likely fallacious, is the basis for the creation of what Schwartz (1992) describes as a regulatory environment which may ultimately prove lethal to human services. In Schwartz's view:

> ...for those of us who have worked hard to erect a "protective wall" ...around vulnerable people, (the failure) of this safeguard approach is disconcerting and is unlikely to be accepted. (p. 164)

In failing to accept that setting standards for practice will not completely eliminate the risk to those being served, Schwartz quite astutely predicts exactly what has evolved in terms of the impact registration inevitably makes on residential projects.

> The expansion of control will, by formalizing and increasing paperwork and related practices, increase the weight under which formalized caregivers must operate, at the cost of individual and organizational vitality. (p. 162)

It seems that in our quest to prevent direct service staff from neglecting the well-being of those they support, the systems that have been designed to ensure this only encourage such neglect by demanding of those staff, increasing amounts of their time to be directed toward compliance to external regulatory processes, rather than toward those they are meant to support. More qualitative inspection processes, involving inspectors spending blocks of time as participant-observers in particular projects, would surely give a more accurate picture of reality and lessen the growing extent, as this study clearly demonstrated, to which direct service staff are guided by registration requirements rather than by person-centred thought processes.

Second, assessments of need must begin to reflect what Wolfensberger (1972) identified many years ago as a fundamental assumption underpinning normalisation: *that people with intellectual disabilities should have a range of opportunities to grow throughout life and that this is a basic human right.* Currently, assessments of need fail to take account of need in relation to social and interpersonal growth, which means that funding made available for support is inadequate to provide people with opportunities to grow in these areas. While likely to be justified as a cost-saving measure in the short-term, such narrow views of the potential of informal sources of support mean that people with intellectual disabilities are unlikely to develop extended networks which may have the capacity to make them less dependent on paid support, and thereby require *less* funding in the longer-term. In other words, short-term investment could lead to long-term savings.

Beyond this simple yet routinely rejected argument of logic however, it was interesting to note that the projects considered in this study, although all involving people with intellectual disabilities assessed to require 24 hour support, operated with a range of different staff-tenant ratios. Those projects involving smaller

numbers of tenants supported in ordinary housing (not based on a cluster model), appeared to have relatively higher staff-tenant ratios. A very simple interpretation of this leads one to conclude that where agencies commit to offering service in ordinary housing (rather than the purpose-built projects considered), they can, on this basis, negotiate higher staff-tenant ratios, for people who would otherwise share a consistent assessment of need. A more complex interpretation may be that where funding has been severely limited in particular areas (since political will has not been sufficiently present), residential providers have reacted by establishing project models which are first and foremost, financially viable. Determining which interpretation one might agree with can prove rather contentious since the simple interpretation suggests that providers using hostel or large, purpose-built project models could, if they wanted to, adopt a philosophical commitment to ordinary housing, which would preclude the establishment of these other models. No doubt the correct interpretation (although there may not be only one) lies somewhere between those offered above. In retrospect, it seems that both those who oversee the design and implementation of community care assessments, as well as those agencies which submit proposals to support people with intellectual disabilities on a block funding basis, should be attempting to ensure that support for the social and interpersonal aspects of lifestyle are included in agreed funding levels.

The third and final change required at policy and systems levels involves the pressing and repeatedly documented need for a reconstitution of the adult training centre. This study confirmed the fact that many people with intellectual disabilities often had to be coerced to attend regularly, did not get along with the majority of other people who attended, and were given very few opportunities to become involved in their local communities or with people who do not have intellectual disabilities. Where this attendance represents a significant portion of someone's

waking hours in a typical week, the negative impact that such an experience has on that person's opportunity to develop relationships and achieve increasing levels of community integration is perhaps more devastating than that resulting from any other factor. In some ways, the re-orientation of residential services toward a community integration agenda would be sharply undermined by the continued existence of adult training centres. The only solution to this wide-spread and totally deplorable state of affairs is the same solution which eventually brought the wide-spread and deplorable conditions in institutions to an end: the development of social policy which commits the government to closure of these adult training centres and the allocation of bridging finance, like that used to stimulate long-stay hospital closures, to enable the similar closure of adult training centres to take place. While it seems likely that once the current hospital closure programmes are complete, advocates will begin to lobby the government for such action to be considered, without the scandals that arose within long-stay hospitals, it is unlikely the government will respond positively.

Conclusion

This study set out to clarify the particular impact that direct service staff have on the relationship network and community integration outcomes of those they support. In general, the study demonstrated that direct service staff are likely to have a critical, and at this point, largely negative role in this regard. The lack of positive community integration experiences, which was shown to typify the lives of many people with intellectual disabilities who live in residential care, can, at a very direct level, be explained by the presence of a single vicious circle. Within this circle, the competing agendas, which are adopted by both the staff teams and the sponsoring

agencies, ultimately distract staff from focusing on relationship network development and community integration, and result in a culture where complacency toward these goals predominates. The power of these competing agendas and the extent of this complacency together mask the resistance which many staff feel toward pursuing relationship network development and community integration agendas.

Emerson and Hatton (1994) raise a range of concerns about the lack of positive outcomes for people with intellectual disabilities beyond those achieved during the relocation & transition phase. This study looked closely at that longer-term post-move period, and the evidence suggested that there is a need to redefine objectives for support which are different from those adopted initially at the point of relocation. For direct support staff teams, evidence suggested these include redefining the emphases on functional independence and the maintenance of existing relationships in favour of a new and sorely needed emphasis on relationship network development and community integration. However, without substantial agency support and leadership, articulated through redefining their own organisational priorities, it is unlikely that direct support staff can achieve the required shift in emphasis that would be needed to generate more positive community integration outcomes for tenants. In addition, agencies will need support from policymakers and purchasers, to ensure that systems practices do not thwart their efforts to address the community integration agenda, and that the era of adult training centres follows that of long-stay hospitals, and becomes part of the past.

Ultimately, it is a question of priorities, but it seems unless community-based residential providers recognise both their own failures to effectively promote

community integration and the extreme importance of redressing this fact in the future, its likely few people with intellectual disabilities who are supported by these agencies can expect any change in their current experiences.

This study has been limited in its focus and attention to staff. It did not adequately address the attitudes of community members, nor did it give sufficient voice to agency managers to define their position and the struggles they face. Clearly, an understanding of the bigger picture is necessary before strategies for change can be comprehensively devised. Yet what is most needed is the commitment of existing agencies to grapple with the realities that this study has demonstrated. Then, strategies for change can be undertaken, researchers can document the outcomes and lessons learned, and through this, *the way forward* will become clear.

[1] This quote taken from the article "Refound Independence: Nobel-Prize winner Halldor Laxness' classic novel *Independent People* reaches a fresh generation of readers in a new US edition." in Atlantica (Summer, 1997) Reykjavik: Icelandic Review.

[2] Some of the most innovative resources include: Amado (*et al.* 1990); Amado (1993); Kretzmann & McKnight (1993); and the range of monographs produced by Communitas, Inc (address in bibliography).

[3] Again, Communitas Inc. has pioneered some very successful examples of housing co-operatives that build community and strengthen the integration of people with disabilities.

[4] For a good discussion of these issues, see (University of Dundee, 1992).

[5] A quote from movie Jerry Macguire (released 1997).

BIBLIOGRAPHY

References

Abbott, A. (1992). 'From Causes to Events: Notes on Narrative Positivism,' *Sociological Methods and Research*, 20(4), pp. 428-455.

Abraham, C. (1989). 'Supporting People with a Mental Handicap in the Community: a social psychological perspective,' *Disability, Handicap & Society*, 4(2), pp. 121-130.

Agar, M. (1986). *Speaking of Ethnography*, London, Sage.

Allen, D. (1988). 'The effects of deinstitutionalisation on people with mental handicaps: A REVIEW,' in *Mental Handicap Research*, pp. 18-37.

Amado, A.N., Conklin, F., and Wells, J. (1990). *Friends: A manual for connecting persons with disabilities and community members*, St. Paul, Human Services Research and Development Center.

Amado, A.N. (1993). *Friendships and Community Connections between People with and without Developmental Disabilities*, Baltimore, Paul H. Brookes.

Argyle, M. and Henderson, M. (1985). 'The Rules of Relationships,' in S. Duck and D. Perlman (eds.) *Understanding Personal Relationships: an interdisciplinary approach*, London, Sage.

Atkinson, D. (1980). 'Moving out of mental handicap hospitals,' *Mental Handicap*, 8(3), pp. 76-78.

Atkinson, D. (1983). 'The community - participation and social contacts,' in O. Russell and L Ward (eds.) *Houses or Homes? Evaluating ordinary housing schemes for people with mental handicap*, London, CEH.

Atkinson, D. (1985). 'With time to spare: leisure pursuits of people with mental handicaps,' *Mental Handicap*, 13(4), pp. 139-40.

Atkinson, D. (1987). 'How easy is it to form friendships after leaving long-stay hospitals?,' *Social Work Today*, June 15, pp. 12-13.

Atkinson, D. (1988). 'Moving from Hospital to the Community: factors influencing the life styles of people with mental handicaps,' *Mental Handicap*, 16, pp. 8-10.

Atkinson, D. (1988a). 'Research interviews with people with mental handicaps,' *Mental Handicap Research,* 1(1), pp. 75-90.

Atkinson, D. (1989). *Someone To Turn To: the social worker's role and the role of front line staff in relation to people with mental handicaps*, Kidderminster, BIMH.

Atkinson, D. and Ward, L. (1987). 'Friends and Neighbours: relationships and opportunities in the community for people with a mental handicap,' in N. Malin (ed.) *Reassessing Community Care*, London, Croom-Helm.

Audit Commission (1986). *Making a Reality of Community Care*, London, HMSO.

Austin, D.M. (1979). 'Research and Social Work: Educational Paradoxes and Possibilities,' *Journal of Social Service Research*, 2(2), pp. 159-175.

Bakeman, R. (1991). 'Analysing Categorical Data,' in B.M. Montgomery and S. Duck (eds.) *Studying Interpersonal Interaction*, New York, The Guilford Press.

Barnes, C. (1992). 'Qualitative Research: valuable or irrelevant?' *Disability, Handicap & Society*, 7(2), pp. 115-124.

Barr, O. (1990). 'Knowledge of and attitudes toward people with mental handicaps: An investigation of RGN students,' *Mental Handicap*, 18, pp. 109-113.

Bavin, J. (1970). 'Subnormality in the seventies - priority in resources,' *Lancet*, 2, pp. 285-7.

Bayley, M. (1973). *Mental Handicap and Community Care: A study of mentally handicapped people in Sheffield*, London, Routledge and Kegan Paul.

Bayley, M. (1997). *What Price Friendship? Encouraging the relationships of people with learning difficulties*, Somerset, Hexagon Publishing.

Bell, N.S. and Schoenrock, C. (1981). 'Changes over time in the community: findings of a longitudinal study,' in R.H. Bruininks (ed.) *Deinstitutionalisation and Community Adjustment of Mentally Retarded People*, Washington DC, American Association on Mental Deficiency.

Bellah, R.N., Madsen, R., Sullivan, M., Swidler, A., Tipton, S.M. (1995). Habits of the Heart: Individualism and Commitment in American Life, Berkley CA, University of California Press.

Birenbaum, A. and Re, M.A. (1979). 'Resettling mentally retarded adults in the community - almost four years later,' *American Journal of Mental Deficiency*, 83(4), pp. 323-329.

Blau, P.M. (1970). 'Decentralisation in Bureaucracies,' in M.N. Zald (ed.) *Power in Organizations*, Nashville TN, Vanderbilt University Press.

Bloom, M. (1986). *The Experience of Research*, London, Macmillan.

Bogdan, R. and Taylor, S. (1987). 'Toward a sociology of acceptance: the other side of the study of deviance, *Social Policy*, Fall, pp. 34-39.

Booth, T., Simons, K., and Booth, W. (1990) *Outward Bound: Relocation and community care for people with learning difficulties*, Milton Keynes, Open University Press.

Booth, T., Bilson, A. and Fowell, I. (1990a). 'Staff attitudes and caring practices in homes for the elderly,' *British Journal of Social Work*, 20, 2 April.

Brekke, J.S. (1986). 'Scientific Imperatives in Social Work Research: Pluralism Is Not Skepticism,' *Social Service Review*, December, pp. 538-551.

Brewer, C. and Lait, J. (1980). *Can Social Work Survive?*, London, Temple Smith.

British Columbia Association for Community Living (1988). *Friendship and People with Mental Handicaps*, Discussion Paper, Vancouver, BCACL.

Bulmer, M. (1987). *The Social Basis of Community Care*, London, Allen and Unwin.

Cambridge, P., Hayles, L. and Knapp, M. (1993). *Care in the Community: Five Years On, PSSRU*, University of Kent.

Campaign for the Mentally Handicapped (1972). *Even Better Services for the Mentally Handicapped: a policy statement*, London, CMH.

Cartwright, D. and Zander, A. (1968). 'Pressure to Uniformity in Groups: Introduction,' in D. Cartwright and A. Zander (eds.) *Group Dynamics: Research and Theory*, London, Tavistock.

Cattermole, M., Jahoda, A., and Markova, I. (1988). 'Leaving home: the experience of people with a mental handicap,' *Journal of Mental Deficiency Research*, 32, pp. 47-57.

Cattermole, M., Jahoda, A. and Markova, I. (1990). 'A Long Day's Journey,' *Nursing Times*, 86(47), pp. 60-62.

Cawson, P. and Perry, J. (1977). 'Environmental correlates of attitudes among residential staff,' *British Journal of Criminology*, 17(2), pp. 141-156.

Central Council for the Education and Training of Social Workers (1989). *Requirements and Regulations for the Diploma in Social Work*, Paper No. 30, London, CEETSW.

Challis, D. and Davies, B.P. (1986). *Case Management in Community Care*, London, Gower.

Challis, D., Darton, R., Johnson, L., Stone, M., Traske, K. and Wall, M. (1989). *Supporting Frail Elderly People at Home*, PSSRU, University of Kent.

Challis, D., Cheesum, R., Chesterman, J., Luckett, R. and Traske, K. (1990). *Case Management in Social and Health Care*, PSSRU, University of Kent.

Cheetham, J., Fuller, R., McIvor, G. and Petch, A. (1992). *Evaluating Social Work Effectiveness*, Buckingham, Open University Press.

Christie, N. (1992). 'Six Ways of Dealing with Stigma: In defence of the ghetto,' in S.R. Baron and J.D. Haldane (eds.) *Community Normality and Difference: meeting special needs*, Aberdeen, Aberdeen University Press.

Cohen, A.P. (1985). *The Symbolic Construction of Community*, London, Routledge.

Cohen, H., Conroy, J.W., Fraser, D.W., Snelbecker, G.E. and Spreat, S. (1977). 'Behavioral effects of interinstitutional relocation of mentally retarded residents,' *American Journal of Mental Deficiency*, 82, pp. 12-18.

Communitas, Inc. - full list of publications available from: P.O. Box 374, Manchester, CT, USA.

Compton, B.R. and Galloway, B. (1994). *Social Work Processes*, Belmont CA, Wadsworth.

Conroy, J.W., Efthimiou, J. and Lemanowitz, J. (1982). 'A matched comparison of the developmental growth of institutionalised and deinstitutionalised mentally retarded clients,' *American Journal of Mental Deficiency*, 86, pp. 581-587.

Corner, J. (1991). 'In search of more complete answers to research questions. Quantitative versus qualitative research methods: is there a way forward?' *Journal of Advanced Nursing*, 16, pp. 718-727.

Crapps, J.M., Langone, J. and Swaim, S. (1985). 'Quantity and quality of participation in community environments by mentally retarded adults,' *Education and Training of the Mentally Retarded*, 20(2), pp. 123-129.

Crawford, J.L., Aiello, J.R. and Thompson, P.E. (1979). 'Deinstitutionalisation and community placement: clinical and environmental factors,' *Mental Retardation*, 17, pp. 59-63.

Davies, B. and Knapp, M. (1988). 'The production of a welfare approach: Evidence and arguments from the PSSRU,' *British Journal of Social Work*, 18, pp. 1-73 (supp).

Davis, F. (1961). 'Deviance Disavowal: The Management of Strained Interaction by the Visibly Handicapped,' *Social Problems*, 9, pp. 120-132.

Davis, K. (1981). 'Grove Road,' *Disability Challenge* (Union of Physically Impaired Against Segregation).

Davis, K.E. and Todd, M.J. (1985). 'Assessing Friendship: Prototypes, paradigm cases and relationship description,' in S. Duck and D. Perlman (eds.) *Understanding Personal Relationships: an interdisciplinary approach*, London, Sage.

Day, P. (1988). 'Not an ordinary life,' *Mental Handicap*, 16, pp. 4-7.

Day, P. (1989). 'Uncertain Future: experiences and expectations of people with mental handicaps of life beyond the hospital and hostel,' *Mental Handicap Research*, 2(2), pp. 166-185.

de Jong, G. (1983). 'Defining and Implementing the Independent Living Concept,' in N. Crewe and I Zola (eds.) *Independent Living for Physically Disabled People*, San Francisco, Jossey Bass.

de Kock, U., Saxby, H., Thomas, M. and Felce, D. (1988). 'Community and family contact: an evaluation of small community homes for adults with severe and profound mental handicaps,' *Mental Handicap Research*, 1(2), pp. 127-140.

Denzin, N. (1978). *The Research Act: A theoretical introduction to sociological methods,* Second Edition, London, McGraw Hill.

Department of Health and Social Security and Welsh Office (1971). Better Services for the Mentally Handicapped, Cmnd 4683, London, HMSO.

Department of Health and Social Security (1976). *Priorities for health and personal social services in England: a consultative document*, London, HMSO.

Department of Health and Social Security (1977). *Priorities in the health and social services: the way forward*, London, HMSO.

Department of Health and Social Security (1980). Mental handicap: progress, problems and priorities, London, HMSO.

Department of Health and Social Security (1981). *Care in the Community: A Consultative Document on Moving Resources for Care in England*, London, DHSS.

Department of Health and Social Security (1981a). *Report of a Study on Community Care*, London, DHSS.

Department of Health and Social Security (1981b). *Care in Action: A handbook of policies and priorities for the health and personal social services in England*, London, HMSO.

Department of Health and Social Security (1984). *The health service in England: Annual Report 1984*, London, HMSO.

Department of Health (1989). *Caring for People: Community Care in the Next Decade and Beyond*, Cmnd 849, London, HMSO.

Dinitto, D., and Dye, T. (1987). *Social Welfare: Politics and Public Policy* (second edition), New Jersey, Prentice-Hall.

Donegan, C. and Potts, M. (1988). 'People with mental handicap living alone in the community: a pilot study of their quality of life,' *British Journal of Mental Subnormality*, 34(1), pp. 10-22.

Duck, S. (1983). *Friends for Life*, Brighton, Harvester.

Duck, S. (1991). 'Diaries and Logs,' in B.M. Montgomery and S. Duck (eds.) *Studying Interpersonal Interaction*, New York, The Guilford Press.

Duffy, M.E. (1985). 'Designing nursing research: the qualitative - quantitative debate, *Journal of Advanced Nursing*, 10, pp. 225-232.

Dutton, G. (1963). 'The mentally subnormal and the hospital,' *British Journal of Mental Subnormality*, 9, Pt. 1.

Edgerton, R.B. (1967). *The Cloak of Competence*, Berkley, University of California Press.

Ennis, E., Rowley, D. and Taylor, L. (1992). *Community care in context*, Dundee, University of Dundee.

Emerson, E. and Hatton, C. (1994). *Moving Out: The Impact of Relocation from Hospital to Community on the Quality of Life of People with Learning Disabilities*, London, HMSO.

Evans, G. and Murcott, A. (1990). 'Community Care: relationships and control,' *Disability, Handicap & Society*, 5(2), pp. 123-135.

Evans, G., Todd, S., Blunden, R., Porterfield, J., and Ager, A. (1987). 'Evaluating the Impact of a Move to Ordinary Housing, *British Journal of Mental Subnormality*, 33(1), 64, pp. 10-18.

Farquharson, R. (1984). *Mentally Handicapped People in Scotland: A Case of Political Neglect*, Edinburgh, Area 5 Action Group.

Fay, B. (1975). *Social Theory and Political Practice*, London, Allen and Unwin.

Felce, D., de Kock, U. and Repp, A.C. (1986). 'An eco-behavioral analysis of small community-based houses and traditional large houses for severely and profoundly handicapped adults,' *Applied Research in Mental Retardation*, 7(4), pp. 393-408.

Felce, D. and Toogood, S. (1988). *Close to home: a local housing service and its impact on the lives of nine adults with severe and profound mental handicaps*, Kidderminster, BIMH.

Festinger, L. (1954). 'A theory of social comparison processes,' in *Human Relations*, 7, pp. 117-40.

Firth, H. and Rapley, M. (1990). *From Acquaintance to Friendship: issues for people with learning disabilities*, Kidderminster, BIMH.

Fischer, J. (1973). 'Is casework effective: A review,' *Social Work*, 17, pp. 1-5.

Flynn, M. (1986). *A study of prediction in the community placements of adults who are mentally handicapped (1983-1986). A summary of the final report,* University of Manchester, Hester Adrian Research Centre.

Flynn, M. (1987). 'The neighbours aren't nice to me,' *Community Living*, September/October, pp. 16-17.

Forest, M. (1987). *It's About Relationships*, Toronto, Frontier College Press.

French, S. (1993). 'Researching disability,' in S. French (ed.) *On Equal Terms: Working with Disabled People*, Oxford, Butterworth-Heinemann.

Galloway, J.F. and Garratt, F.N. (1964). 'Hospitals for the mentally subnormal and the local health authority,' *British Journal of Mental Subnormality*, 10, Pt. 1.

Gilloran, A.J., McGlew, T., McKee, K., Robertson, A. and Wight, D. (1993). 'Measuring the quality of care in psycho-geriatric wards,' in *Journal of Advanced Nursing*, 18, pp. 269-275.

Glaser, B.G. and Strauss, A.L. (1967). The Discovery of Grounded Theory: Strategies for Qualitative Research, New York, Aldine Publishing Company.

Goffman, I. (1961). *Asylums: essays on the social situation of mental patients and other inmates*, Garden City, Doubleday.

Gollay, E., Freedman, R., Wyngaarden, M. and Kurtz, N.R. (1978). *Coming Back*, Cambridge MA, ABT Associates.

Gray, A.M. and Mooney, G.H. (1982). 'Health in Scotland,' in Cuthbert, M. (ed.) *Government spending in Scotland*, Edinburgh, Paul Harris.

Griffiths, Sir R. (1988). *Community Care: Agenda for Action*, London, HMSO.

Griffiths, Sir R. (1990). *With due care and attention: reflections on health and community care*, lecture given at the University of Edinburgh, 19 November.

Grinnell, R.M. (1988). *Social Work Research and Evaluation*, Itasca IL, F. E. Peacock.

Grunewald, K. (1974). *The Mentally Retarded in Sweden*, Stockholm, The Swedish Institute.

Gunzberg, H.C. (1957). 'Therapy and social training for the feebleminded youth,' *British Journal of Mental Subnormality*, 13, pp. 86-7.

Gunzberg, H.C. (1968). *Social Competence and Mental Handicap*, London, Balliere, Tindall and Cassell.

Hailey M. (1992). 'The Origins and Development of Camphill Communities,' in S.R. Baron and J.D. Haldane (eds.) *Community Normality and Difference: Meeting Special Needs*, Aberdeen, Aberdeen University Press.

Hakim, C. (1987). *Research Design: Strategies and Choices in the Design of Social Research*, London, Allen and Unwin.

Hanson, N. (1958). *Patterns of discovery*, Cambridge, Cambridge University Press.

Hartzler, E. (1951). 'A follow-up study of girls discharged from the Laurelton State Village,' *American Journal of Mental Deficiency*, 56, pp. 612-18.

Heineman, M.B. (1981). 'The Obsolete Scientific Imperative in Social Work Research,' *Social Service Review*, September, pp. 371-397.

Herriott, R.E. and Firestone, W.A. (1983). 'Multisite qualitative policy research: Optimizing description and generalizability,' *Educational Researcher*, 12, pp. 14-19.

Hiatt, M.S. (1951). 'Casework services in community placement of mental defectives,' *American Journal of Mental Deficiency*, 56, No. 1.

Hill, B.K., Rotegard, L.L. and Bruininks, R.H. (1984). 'The Quality of Life of Mentally Retarded People in Residential Care,' *Social Work*, May/June, pp. 275-280.

Hogan, R. (1986). 'Gaining community support for group homes,' *Community Mental Health Journal*, 22, pp. 26-36.

Holland, T. (1973). 'Organizational structure and institutional care,' *Journal of Health and Social Behavior*, 14, pp. 241-251.

Holmes, M.E. and Poole, M.S. (1991). 'Longitudinal Analysis,' in B.M. Montgomery and S. Duck (eds.) *Studying Interpersonal Interaction*, New York, The Guilford Press.

Homans, G.C. (1951). *The Human Group*, London, Routledge and Kegan Paul.

Home Office, Department of Education and Science, Ministry of Housing and Local Government, Ministry of Health (1968). *Report of the Committee on Local Authority and Allied Personal Social Services* (The Seebohm Report), Cmnd 3703, London, HMSO.

House of Commons Social Services Committee (1985). *Community care with special reference to adult mentally ill and mentally handicapped people,* Second report, session 1984-5, HC 13-1, London, HMSO.

Howarth, G.O. (1984). 'Social work research, practice, and paradigms,' *Social Service Review*, 58, pp. 343-357.

Howe Report (1969). *Report of the Committee of Enquiry into Allegations of Ill-treatment of Patients and Other Irregularities at the Ely Hospital, Cardiff*, Cmnd 3795, London, HMSO.

Humphreys, S., Evans, G. and Todd, S. (1987). *Lifelines: an account of the life experiences of seven people with mental handicap who use the NIMROD service,* London, King Edward's Hospital Fund for London.

Hunter, D.J. and Wistow, G. (1987). Community Care in Britain: Variations on a Theme, London, King Edward's Hospital Fund for London.

Hutchison, P. and McGill, J. (1990). *Community, Integration, and Leisure*, Toronto, Leisurability Publications.

Jahoda, A., Cattermole, M., and Markova, I. (1990). 'Moving out: an opportunity for friendship and broadening social horizons,' *Journal of Mental Deficiency Research*, 34, pp. 127-139.

Jay Committee (1979). *Report of the Committee of Enquiry into Mental Handicap Nursing and Care*, Cmnd 7468, London, HMSO.

Jones, K. (1975). *Opening the Door: a study of new policies for the mentally handicapped*, London, Routledge and Kegan Paul.

Kagle, J.D. and Cowger, C.D. (1984). 'Blaming the Client: Implicit Agenda in Practice Research?,' *Social Work*, July/August, pp. 347-351.'

Kane, R. (1982). 'Lessons for Social Work from the Medical Model: A Viewpoint for Practice,' *Social Work*, 27, pp. 55-69.

Kaplan, A. (1964). *The conduct of inquiry*, Scranton PA, Chandler.

Kaufman, S. (1984). 'Friendship, coping systems and community adjustment of mentally retarded adults,' in R.B. Edgerton (ed.) *Lives in Process: Mildly Retarded Adults in a Large City*, AAMD Monograph, No. 6.

Kennedy, J. and Ritchie, P. (1994). *Community Living: implications for people and agencies*, Edinburgh, SHS Ltd.

Kevles, D. (1986). *In the Name of Eugenics*, Harmondsworth, Penguin.

King, R.D., Raynes, N.V., and Tizard, J. (1971). *Patterns of Residential Care: Sociological Studies in Institutions for Handicapped Children*, London, Routledge and Kegan Paul.

Kings Fund Centre (1980). *An Ordinary Life: comprehensive locally-based services for mentally handicapped people*, Project Paper 24, London, Kings Fund.

Kings Fund Centre (1988). *Ties and connections: an ordinary community life for people with learning difficulties*, London, Kings Fund.

Kings Fund Centre (1991). *Meeting the Challenge: Some UK perspectives on community services for people with learning difficulties and challenging behaviour*, London, Kings Fund.

Kingsley, L.V. and Hyde, R.W. (1945). 'The Health and Occupational Adequacy of the Mentally Deficient,' *Journal of Abnormal Social Psychology*, 40, pp. 37-46.

Kinsella, P. (1993). *Supported Living: A New Paradigm,* Manchester, National Development Team.

Korman, N. and Glennerster, H. (1985). *Closing a Hospital - the Darenth Park Project*, London, London School of Economics and Political Science.

Landesman, S. and Butterfield, E.C. (1987). 'Normalization and deinstitutionalization of mentally retarded individuals: Controversy and facts,' *American Psychologist*, 42(8), pp. 809-16.

Laxness, H. (1997). *Independent People*, New York, Random House.

Le Touze, S. and Pahl, J. (1992). 'Facilitating Friendships for People with Learning Disabilities,' *Mental Handicap*, 20, pp. 144-148.

Locker, D., Rao, B. and Weddell, M. (1983). 'The impact of hostel care on mentally handicapped adults,' *Mental Handicap*, 11(3), pp. 100-103.

Lofland, J. (1971). *Analyzing Social Settings: A Guide to Qualitative Observation and Analysis*, Belmont CA, Wadsworth.

Lowe, K. and de Paiva, S. (1990). *The Evaluation of NIMROD, a community based service for people with mental handicap*, Cardiff, Mental Handicap in Wales - Applied Research Unit.

Lundstrom-Roche, F. (1981). *Our Lives*, Irish National Committee for the International Year of Disabled People, Dublin.

Lutfiyya, Z.M. (1988). 'Other than clients: reflections on relationships between people with disabilities and typical people,' *TASH Newsletter*, September, pp. 2-6.

Macdonald, G., Sheldon, B. and Gillespie, J. (1992). 'Contemporary Studies of Social Work Effectiveness,' *British Journal of Social Work*, 22(6), pp. 615-643.

Malin, N. (1982). 'Group homes for mentally handicapped adults: Residents' views on contact and support, *British Journal of Mental Subnormality*, 28(2), pp. 29-34.

Martin, F.M. (1984). *Between the acts: Community mental health services 1959-1983*, London, The Nuffield Provincial Hospitals Trust.

Martin, J.P. (1984). *Hospitals in Trouble*, Oxford, Basil Blackwell.

Martindale, A. and Kilby, C.A. (1982). Closure of an old mental handicap hospital and the short-term and long-term effects on residents,' *British Journal of Mental Subnormality*, 28(1), pp. 3-12.

Maslow, A.H. (1954). *Motivation and Personality*, New York, Harper & Row.

Mauthner, M. and Dussett, R. (1997). 'Reflections on a voice-centred relational model,' in J. Ribbens and R. Edwards (eds.) *Feminist dilemmas in qualitative research*, London, Sage.

McConkey, R., Walsh, J. and Mulcahy, M. (1982). 'Mentally handicapped adults living in the community - a survey in and around the city of Dublin,' *Mental Handicap*, 10, pp. 90-93.

McConkey, R., Naughton, M. and Nugent, U. (1983). 'Have we met? Community contact of adults who are mentally handicapped,' *Mental Handicap*, 11, pp. 57-59.

McConkey, R. (1987). *Who Cares? Community involvement with mental handicap*, London, Souvenir Press.

McConkey, R. (1989). *Community Reactions to Group Homes: Contrasts between people living in areas throughout Ireland with and without group homes*, Dublin, St. Michael's House Research Trust.

McDevitt, S.C., Smith, P.M., Schmidt, D.W. and Rosen, M.R. (1978). 'The deinstitutionalised citizen,' *Mental Retardation*, 18, pp. 22-24.

McKnight, J. (1987). 'Regenerating Community,' *Social Policy*, Winter, pp. 54-58.

Miles, M.B. and Huberman, A.M. (1994). *Qualitative Data Analysis: An Expanded Sourcebook*, Second Edition, London, Sage.

Morris, P. (1969). *Put Away: a sociological study of institutions for the mentally retarded*, London, Routledge and Kegan Paul.

Morris, J. (1993). *Independent Lives: community care and disabled people*, London, Macmillan.

Mullen, E.J. and Dumpson J.R. (1972). *Evaluation of Social Work Intervention*, New York, Jossey-Bass.

National Development Group for the Mentally Handicapped (1978). *Helping Mentally Handicapped People in Hospital*, London, NDG.

National Institute for Social Work (1982). *Social Workers: Their Role and Tasks* (The Barclay Report), London, Bedford Square Press.

Newman, D. and Rowbottom, R.W. (1968). *Organization Analysis: A guide to the better understanding of the structural problems of organizations*, London, Heinemann.

Newman, D. (1973). *Organization Design: An analytical approach to the structuring of organizations*, London, Edward Arnold.

Newnes, C. (1994). 'A Commentary on Obstacles in the Professional Human Service Culture to Implementation of Social Role Valorization and Community Integration of Clients,' *Care In Place*, 1(1), pp. 57-64.

News of the World, 20 August, 1967.

Nirje, B. (1969). 'The normalization principle and its human management implications,' in R. Kugel and W. Wolfensberger (eds.) *Changing Patterns in Residential Services for the Mentally Retarded*, Washington, D.C., Presidents' Committee on Mental Retardation.

Nisbet, J. (!992). *Natural Supports in School, at Work, and in the Community for People with Severe Disabilities*, Baltimore, Paul H. Brookes.

O'Brien, J. and Tyne, A. (1981). *The principle of normalisation: a foundation for effective services*, London, CMH.

O'Brien, J. (1987). 'A guide to personal future planning,' in G.T. Bellamy and B. Wilcox (eds.) *A comprehensive guide to the activities catalog: an alternative curriculum for youth and adults with severe disabilities,* Baltimore, Paul H. Brookes.

O'Brien, J. and Lyle, C. (1990). *Framework for Accomplishment*, Georgia, Responsive Systems Associates.

O'Connor, N. and Tizard, J. (1954). 'A survey of patients in twelve mental deficiency institutions,' in *British Medical Journal*, 1, pp. 16-20.

O'Connor, N. and Tizard, J. (1956). *The Social Problem of Mental Deficiency*, London, Pergamon.

Oswin, M. (1978). *Children Living in Long-stay Hospitals*, Spastics International Medical Publications, Monograph No. 5, London, Heinemann Medical Books, Ltd.

Race, D. (1995). 'Historical development of service provision,' in N. Malin (ed.) *Services for people with learning disabilities*, London, Routledge.

Rawlings, S.A. (1985). 'Life-styles of Severely Retarded Non-communicating Adults in Hospitals and Small Residential Homes,' *British Journal of Social Work*, 15, pp. 281-293.

Rawlings, S.A. (1985a). 'Behaviour and Skills of Severely Retarded Adults in Hospitals and Small Residential Homes,' *British Journal of Psychiatry*, 146, pp. 358-366.

Raynes, N.V., Pratt, M. and Roses, S. (1979). *Organisational Structure and the Care of the Mentally Retarded*, London, Croom Helm.

Raynes, N.V., Sumpton, R.C. and Flynn, M.C. (1987). *Homes for mentally handicapped people*, London, Tavistock.

Raynes, N.V. (1988). *Annotated Directory of Measures of Environmental Quality*, University of Manchester, Department of Social Policy and Social Work.

Reid, W.J. and Hanrahan, P. (1981). 'The Effectiveness of Social Work: Recent evidence,' in E.M. Goldberg and N. Connelly (eds.) *Evaluative Research in Social Care*, London, Heinemann.

Reiter, S. and Levi, A.M. (1980). 'Factors affecting social integration of non-institutionalised mentally retarded adults,' *American Journal of Mental Deficiency,* 85, pp. 25-30.

Report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency (1954-57). presented to Parliament May, 1957, London, HMSO.

Richardson, A. and Ritchie, J. (1989). *Developing friendships: enabling people with learning difficulties to make and maintain friends*, London, Policy Studies Institute.

Rioux, M.H. (1994). 'New Research Directions and Paradigms: Disability Is Not Measles,' in M.H. Rioux & M. Bach (eds.) *Disability Is Not Measles: New Research Paradigms in Disability*, North York ONTARIO, Roeher Institute.

Ritchie, P. (1994). 'Community Care - a quick look at some big issues,' in R. Davidson and S. Hunter (eds.) *Community Care in Practice,* London, Batsford.

Robson, C. (1993). *Real World Research: A Resource for Social Scientists and Practitioner-Researchers*, Oxford, Blackwell.

Roycroft, P. and Hames, A. (1990). 'Local objections to community-based houses for people with mental handicaps: factors for consideration,' *Mental Handicap*, 18, pp. 11-14.

Rubin, Z. (1980). *Children's Friendships*, Cambridge MA, Harvard University Press.

Rubin, A. and Babbie, E. (1989). *Research Methods for Social Work*, Belmont CA, Wadsworth.

Ryan, W. (1971). *Blaming the Victim*, New York, Pantheon Books.

Sarason, S.B. (1974). *The Psychological Sense of Community: Prospects for a Community Psychology*, San Francisco, Jossey-Bass.

Saxby, H., Thomas, M., Felce, D. and Kock, U. (1986). 'The use of shops, cafes and public houses by severely and profoundly mentally handicapped adults,' *British Journal of Mental Subnormality*, 32, pp. 69-81.

Schalock, R.L. and Kiernan, W.E. (1990). *Habilitation Planning for Adults with Disabilities*, New York, Springer-Verlag.

Schatzman, L. and Strauss, A. (1973). *Field Research: Strategies for a Natural Sociology*, Englewood Cliffs NJ, Prentice-Hall.

Schwartz, D.B. (1992). *Crossing the River: Creating a Conceptual Revolution in Community and Disability*, Brookline MA, Brookline Books.

Scottish Home and Health Department & Scottish Education Department (1964). *Children and Young Persons Scotland* (The Kilbrandon Report), Cmnd 2306, Edinburgh, HMSO.

Scottish Home and Health Department and Scottish Education Department (1972). *Services for the mentally handicapped*, Edinburgh, SHHD.

Scottish Home and Health Department (1976). *The health service in Scotland: the way ahead*, Edinburgh, HMSO.

Scottish Home and Health Department and Scottish Education Department (1979). *A better life: report on services for the mentally handicapped in Scotland*, Edinburgh, HMSO.

Scottish Home and Health Department (1980). *Scottish health authorities priorities for the eighties*, Edinburgh, HMSO.

Scottish Home and Health Department (1980a). *Joint planning and support financing arrangements*, NHS Circular 1980(GEN)5, Edinburgh, SHHD.

Seed, P. (1990). *Introducing Network Analysis in Social Work*, London, Jessica Kingsley.

Seltzer, M.M. (1985). 'Public Attitudes Toward Community Residential Facilities for Mentally Retarded Persons,' in R.H. Bruininks and K.C. Lakin (eds.) *Living and Learning in the Least Restrictive Environment*, Baltimore, Paul H. Brookes.

Sheldon, B. (1986). 'Social Work Effectiveness Experiments: review and implications,' *British Journal of Social Work,* 16, pp. 223-242.

Siegelman, C., Budd, E.C., Spaniel, C. and Schoenrock, C. (1981). 'Asking questions of retarded persons: A comparison of yes-no and either-or formats,' *Applied Research in Mental Retardation*, 2, pp. 347-357.

Sinclair, I. (1975). 'The influence of wardens and matrons in probation hostels,' in J. Tizard, I. Sinclair and R. Clarke (eds.) *Varieties of Residential Experience*, London, Routledge and Kegan Paul.

Sinson, J. (1993). *Group Homes and Community Integration of Developmentally Disabled People: Micro-Institutionalistion?*, London, Jessica Kingsley.

Smiley, C.W. (1982). 'Managing Agreement: The Abilene Paradox,' in *Community Development Journal*, 17(1), pp. 54-59.

Smith, G. and Cantley, C. (1985). *Assessing Health Care: A study in organisational evaluation*, Milton Keynes, Open University Press.

Snow, J. (1990). *Support Circles Workshop Proceedings*, Kitchener ONT, Community Network for Education and Training.

Stainback, W. and Stainback, S. (1987). 'Facilitating Friendships,' *Education and Training in Mental Retardation*, March. pp. 18-25.

Stake, R.E. (1994). 'Case Studies,' in N. Denzin and Y. Lincoln (eds.) *Handbook of Qualitative Research*, London, Sage.

Stake, R.E. (1995). *The Art of Case Study Research*, London, Sage.

Stanworth, M. (1989). 'The new eugenics,' in A. Brechin and J. Walmsley (eds.) *Making Connections: Reflecting on the Lives and Experiences of People with Learning Difficulties*, London, Hodder and Stoughton.

Stern, P. (1980). 'Grounded theory methodology: its uses and processes,' *Image*, 12, pp. 20-23.

Strauss, A. and Corbin, J. (1994). 'Grounded Theory Methodology: An Overview,' in N. Denzin and Y. Lincoln, (1994). *Handbook of Qualitative Research*, London, Sage.

Szivos, S. (1992). 'The limits to integration?' in H. Brown and H. Smith (eds.) *Normalisation: A reader for the nineties*, London, Routledge.

Taylor, S.J. (1988). Caught in the continuum: 'A critical analysis of the principle of the least restrictive environment,' *Journal of the Association for Persons with Severe Handicaps*, 13(1), pp. 41-53.

Tizard, J. and O'Connor, N. (1952). 'The occupational adaptation of high-grade defectives,' in *Lancet*, 2, pp. 620-3.

Tizard, J. and Grad, J.C. (1961). *The Mentally Handicapped and their Families: a Social Survey*, London.

Tizard, J. (1964). *Community Services for the Mentally Handicapped*, London, Oxford University Press.

Tredgold, A.F. (1908). *A Textbook on Mental Deficiency* (first edition), London, Balliere, Tindall and Cox.

Tredgold, A.F. (1909). 'The feebleminded - a social danger,' in *Eugenics Review*, 1, pp. 97-104.

Tredgold, A.F. (1952). *A Textbook on Mental Deficiency (Amentia)*, eighth edition, London, Balliere, Tindall and Cox.

Tyne, A. (1987). 'Shaping Community Services: The Impact of an Idea,' in N. Malin (ed.) *Reassessing Community Care*, London, Croom Helm.

Tyne, A. (1992). 'Normalisation: from theory to practice,' in H. Brown and H. Smith (eds.) *Normalisation: A reader for the nineties*, London, Routledge.

United Nations General Assembly (1972). *Declaration on the Rights of Mentally Retarded Persons, Resolution 2856*, 26th Session.

University of Dundee (1992). *Community care and the boundary between housing and support*, Department of Social Work research paper, Dundee, University of Dundee.

Vanier, J. (1979). *Community and Growth: Our Pilgrimage Together*, Toronto: Griffin House.

Vaughan, D. (1992). 'Theory elaboration: the heuristics of case analysis,' in C.C. Ragin and H.S. Becker (eds.) *What is a Case? Exploring the foundations for social inquiry*, Cambridge, Cambridge University Press.

Walker, P. (1995). 'Community Based Is Not Community,' in S. Taylor, R. Bogdan, and Z.M. Lutfiyya (eds.) *The Variety of Community Experience: Qualitative Studies of Family and Community Life*, Baltimore, Paul H. Brookes.

Wallace, W. (1971). *The Logic of Science in Sociology*, Chicago IL, Aldine-Atherton.

Wallace, A. and Rees, S. (1984). 'The priority of client evaluations,' *Research Highlights*, University of Aberdeen, No. 8, pp. 68-84.

Walmsley, J. (1994). 'Learning disability: overcoming the barriers?' in S. French (ed.) *On Equal Terms: Working with Disabled People*, Oxford, Butterworth-Heinemann.

Wellman, D.T. (1977). *Portraits of White Racism*, Cambridge, Cambridge University Press.

Welsh Office (1983). *All Wales strategy for the development of services for mentally handicapped people*, Cardiff, Welsh Office.

Welsh Office (1983a). *Health and social services development: 'care in the community' - services for people who are mentally handicapped, mentally ill, elderly or physically handicapped*, Welsh Office circular 15/83, Cardiff, Welsh Office.

Wertheimer, A. (1986). *Hospital Closures in the Eighties*, London, CMH.

Whittaker, J.K. and Garbarino, J. (1983). *Social Support Networks: Informal Helping in the Human Services*, New York, Aldine Publishing Company.

Wilcox, B.L. (1981). 'Social support in adjusting to marital disruption,' in B.H. Gottlieb (ed.) *Social Networks and Social Support*, Beverly Hills, Sage.

Willer, B. and Intagliata, J. (1982). 'Comparison of family-care and group homes as alternatives to institutions,' *American Journal of Mental Deficiency*, 86(6), pp. 588-595.

Williams, P. and Tyne, A. (1988). 'Exploring values as the basis for service development,' in D. Towell (ed.) *An Ordinary Life in Practice: Developing comprehensive community-based services for people with learning disabilities*, London, King Edward's Hospital Fund for London.

Willmott, P. (1987). *Friendship Networks and Social Support*, Research Report No. 666, London, Policy Studies Institute.

Wimsatt W. (1980). 'Reductionistic Research Strategies and their Biases in the Units of Selection Controversy,' in T. Nickles (ed.) *Scientific Discovery: Case Studies*, Hingham MA, Reidel Publishing Company.

Wolfensberger, W. (1972). *The Principle of Normalisation in Human Services*, Toronto, National Institute on Mental Retardation.

Wolfensberger, W. (1975). *The Origin and Nature of Our Institutional Models*, Syracuse, Human Policy Press.

Wolfensberger, W. (1975a). 'Values in the Field of Mental Health as They Bear on Policies of Research and Inhibit Adaptive Human-Service Strategies,' in J.C. Schoolar and C.M. Gaitz (eds.) *Research and the Psychiatric Patient*, New York, Brunner/Mazel.

Wolfensberger, W. and Glenn, L. (1975). *PASS 3*, Toronto, National Institute of Mental Retardation.

Wolfensberger, W. (1979). 'An attempt toward a theology of social integration of devalued/handicapped people,' *Information Service*, 8(1), pp. 12-26.

Wolfensberger, W. (1983). 'Social role valorisation: a proposed new term for the principle of normalisation,' *Mental Retardation*, 21(6), pp. 234-9.

Wolfensberger, W. and Thomas, S. (1983). *PASSING*, Toronto, National Institute on Mental Retardation.

Wolfensberger, W. (1994). 'Let's Hang Up "Quality of Life" As a Hopeless Term,' in D. Goode (ed.) *Quality of Life for Persons with Disabilities: International Perspectives and Issues*, Cambridge MA, Brookline Books.

Wolfensberger, W. and Thomas, S. (1994). 'Obstacles in the Professional Human Service Culture to Implementation of Social Role Valorization and Community Integration of Clients,' *Care In Place*, 1(1), pp. 53-56.

World Health Organization (1954). *The Mentally Subnormal Child*, Geneva, WHO.

Wyatt vs. Stickney (1972). 344 F. Supp. 373, 387 (M.D. Ala. 1972), aff'd sub nom, *Wyatt vs, Alderholt*, 503 F. 2d. 1305 (5th Cir.).

Yin, R.K. (1981). 'The Case Study as a Serious Research Strategy,' *Knowledge: Creation, Diffusion, Utilization*, 3(1), pp. 97-114.

Yin, R.K. (1994). *Case Study Research: Design and Methods*, Applied Social Research Methods Series (Volume 5), London, Sage.

Zimbardo, P.G. and Ebbesen, E.B. (1969). *Influencing Attitudes and Changing Behavior: a basic introduction to relevant methodology, theory and applications*, Reading MA, Addison-Wesley Publishing Company.

Acts of Parliament

Disabled Persons (Services, Consultation, and Representation) Act (1986). London, HMSO.

Mental Deficiency Act (1913). London, HMO.

Mental Health Act (1959). London, HMSO.

National Health Service Act (1946). London, HMSO.

National Health Service and Community Care Act (1990). London, HMSO

APPENDIX

The Concept of Full Integration

1. From the development of facilities and programs into which people must fit to the provision of services and supports necessary for people with disabilities to participate fully in community life.

2. From neighborhoods to typical homes and from vocational models to typical jobs and activities.

3. From professional judgement as a basis for determining community involvement to personal choice.

4. From a presumption in favor of integration to a mandate to provide opportunities for integration.

5. From a conditional ("to the extent necessary, appropriate, feasible") to an unconditional commitment to integration.

6. From requiring individuals to change in order to participate in the community to requiring service systems to change.

7. From restrictions applied categorically as a condition for receiving services to opportunities available to nondisabled people.

8. From disability labels as a factor in determining community participation to a recognition of common human needs.

9. From independence to community belonging.

10. From placing people in the community to helping them become part of the community.

Source: Taylor (1988).

A Paradigm Case of Friendship

1. Participate as equals, in the sense that those things that one person is eligible to do the other is also eligible to do (equality);

2. Enjoy each other's company. Such enjoyment needs to be understood as a dispositional characteristic of the relationship... if enjoyment were not the norm, it would make continued association difficult (enjoyment/attraction);

3. Have a relationship of mutual trust in the sense that each takes it that the other person will act in light of her or his friend's best interest (trust);

4. Are inclined to provide each other with assistance and support, and specifically, to count on each other in times of need, trouble, or personal distress (mutual assistance);

5. Accept each other as they are, without being inclined to change or make the other over into a new, different person (acceptance);

6. Respect each other, in the sense of taking it that each recognises good judgement in his or her life choices (respect);

7. Feel free to be themselves in their relationship, rather than feeling required to play a role, wear a mask, or inhibit expressions of their personal characteristics (spontaneity);

8. Have come to understand each other, not merely in the sense of knowing facts about each other, but in the more fundamental sense of understanding the rationale of each other's behavior (understanding);

9. Are intimate, in the sense that sharing experiences by virtue of doing things together and, in many cases, by virtue of confiding in each other (intimacy).

Source: Davis & Todd (1985)

PROTOTYPES FOR RELATIONSHIP CATEGORIES:

INTIMATE FRIEND (not a relative or spouse)

A. There are feelings of mutual attraction and attachment and both friends desire to spend their free time with the other. Both feel the relationship would not fade away if the friends were seperated by distance or time.

B. There is trust and intimacy, where each friend feels secure in sharing deep feelings and thoughts. Each friend keeps the confidences of the other and each friend is sensitive to the feelings of the other.

C. There are feelings of mutual respect and acceptance for the other friend and the things he/she does. Each friend is proud to be associated with the other, and treats the other as an equal.

D. Each friend is willing to offer unconditional assistance and resources of any kind to help the other out of a tough situation.

1. _____

2. _____

3. _____

4. _____

5. _____

FRIEND

A. Both have a general liking for each other, but there are no strong feelings of attachment or commitment. Both share a continuing relationship based on social contact. Without regular social contact, it is questionable whether the relationship would sustain itself.

B. Both usually share common interests beyond the relationship itself, that encourages continued social contact. (e.g. work, common group of friends, social club, organisation, or hobbie)

C. Both share a level of trust and sharing, though very personal issues and problems are not openly shared.

D. Assistance is likely to be regularly requested and given, though this would not typically include very demanding kinds of assistance and support.

1. _____

2. _____

3. _____

4. _____

5. _____

SOCIAL ACQUAINTANCE

A. Both recognise each other when seen, and both would normally greet the other and/or share casual conversation.

B. There are no planned meetings between the two people, and they typically encounter each other because of mutual involvement in some organised activity or living/working/socialising in a geographically proximate area.

C. If both have something in common (eg. work, social club, sports team, town resident), the relationship does not continue beyond this. There is generally no interaction in either person's home, though both may attend social gatherings together.

D. Neither rely upon the other for assistance or support on a regular basis, though the knowledge and information of acquaintances are often shared in casual conversation.

1. _____

2. _____

3. _____

4. _____

5. _____

ADULT RELATIVE

A. Any relationship of kinship, by birth, marriage, or remarriage/adoption with whom, regular contact is maintained by post, phone, or in person.

1. _____

2. _____

3. _____

4. _____

5. _____

PROFESSIONAL (not a work colleague)

A. Any individual who provides you with a good or service for which he or she receives a fee or wage from you or some source.

B. All meetings involve the provision of a good or service, even if there are genuine feelings of friendliness and affection between the two people. There is no regular contact that is of a purely social and voluntary nature.

1. _____

2. _____

3. _____

4. _____

5. _____

Name of tenant: Name of staff member:

POST-MOVE RELATIONSHIP NETWORK #2 **(month/year)**

Names in Italics - People with L.D.

Intimate Friend **Friend**

Social Acquaintance **Adult Relative**

Professional

Agency Other segregated services Community

LIST OF SCENARIOS: (1)=first choice; (2)=second choice;
(3)=third choice; (4)=would not call on.

Scenario	(1)	(2)	(3)	(4)	comments
Help you move house.					
Water your plants while you're away on two-week holiday.					
Help you celebrate a new job/promotion/raise.					
Return your overdue library books to the local library.					
Take care of your dog while you're away for two weeks.					
Help you deal with a fight with your parents.					
Help you celebrate your birthday by going out with you.					
Lend you £10. if the local bank/ bank machine is closed.					
Pick you up at the airport after your holiday.					
Give you milk if you run out & the shop is closed.					
Lend you a corkscrew.					
Help you deal with a death in your family.					
Help you prepare food for a cocktail party you're hosting.					
Come visit you when you are in hospital.					
Go with you to a movie/play you want to see.					
Help you put up new wallpaper in your home.					

Scenario	(1)	(2)	(3)	(4)	comments
Help you deal with a fight with your best friend.					
Meet you for a drink after work.					
Go shopping with you for Christmas presents.					
Help you if you need a character witness in court.					
Go on holiday with you.					
Celebrate New Years with you.					
Help you deal with a fight with your sibling.					
Lend you their camera to take on holiday.					
Organise a surprise birthday party for you (21-30-40-50).					
Help you deal with losing your job.					
Co-sign on a loan you need from the bank.					
House sit while you are away.					
Give you a place to stay in an emergency (fire in your house)					
Meet you for a drink on Saturday night.					
Help you build furniture you bought in kit form.					
Help you deal with being unsuccessful in a job interview.					
Go with you to try a new restaurant that just opened.					
Rent a movie to watch with you when you're bored one night.					

Scenario	(1)	(2)	(3)	(4)	comments
Come stay with you when you phon up and say you've just received some bad news.					
Give you plants from their garden to start your garden with					
Get you some soup from the shop if you are suddenly ill in bed.					
Stop in to visit you when they are driving through your area.					
Help you deal with a fight with your spouse.					
Write you a reference for a job you are applying for.					

DATE:

What happened today? What did you do today? Where did you go today?	Who were you with? (use full name)	Who did you meet? (use full name)
Morning:		
Afternoon:		
Evening:		

WHAT'S YOUR POINT OF VIEW?

In this section, a list of statements are presented regarding a number of issues that you may encounter as a member of staff. For each statement, you are asked to comment on the degree to which you agree or disagree with the statement by ticking one of the five choices along the spectrum of agreement & disagreement. There are no right or wrong answers, just answer according to what you think.

STATEMENT	strongly agree	somewhat agree	no opinion	somewhat disagree	strongly disagree
People with a mental handicap grow best when they work with a small, familiar group of staff that don't change.					
There are no people who can't communicate their feelings in some way.					
We cannot expect to understand the odd behaviour of some people with a mental handicap.					
Management cares about its staff.					
People who don't want to move out of hostel or hospital should not be forced to move					
People with a mental handicap who can't communicate verbally have more trouble making friends than those who can communicate verbally.					
Management gives mixed messages about what it expects of its staff.					

STATEMENT	strongly agree	somewhat agree	no opinion	somewhat disagree	strongly disagree
People who don't like certain individuals should not be forced to live with these people.					
Kindness is more important than a therapeutic programme for people with a mental handicap.					
Management likes staff who show independence and initiative.					
The most important factor in friendship is that the two friends should share similar interests.					
Single flats for handicapped people will cause them to become isolated.					
Handicapped people have to understand that they can't have everything they may want or need because there just isn't enough money.					
If people are happy with their lives, they shouldn't be expected to try new things.					
Management keeps its promises.					

STATEMENT	strongly agree	somewhat agree	no opinion	somewhat disagree	strongly disagree
The handicapped people I work with have life better than me in some ways.					
The more the staff, the better the quality of life for the individuals we work with.					
Management likes what its staff are doing.					
Choice makes people more greedy and selfish.					
Handicapped people are more sensitive to the feelings of others than non-handicapped people.					
People who don't like certain staff should not be forced to spend time with these staff members.					
When working with handicapped people, formal training is more important than commonsense.					
Genuine friendships can reduce behaviour problems.					
Management doesn't admit when it fails to achieve what it intended to achieve.					

STATEMENT	strongly agree	somewhat agree	no opinion	somewhat disagree	strongly disagree
Handicapped people don't know as much about friendship as non-handicapped people.					
Management fights for what's best for the residents.					
There is nothing wrong with changing one's mind.					
The smaller a house, the better the quality of life for the individuals we work with.					
Family involvement is good for people with a mental handicap.					
Management doesn't show appreciation for efforts of staff.					
Sincere friendships cannot develop in hostels or hospitals.					
We cannot expect to understand the odd behaviour of some people with a mental handicap.					
People with behaviour problems should not be held back from community living.					
If an individual with a mental handicap can't communicate well, people think he/she cannot make choices/decisions.					

Please Turn Over

PROJECT STAFF TEAM "A"

Activities/Actions

1. Attention to intra-project relationships, particularly to the need to minimise dispute or infringement between tenants and the decision to pursue group activities, far outweighs attention paid to tenants developing relationships beyond the project.

2. The predominance of a home-based, functional independence agenda is reflected in both the staff team's priorities and the tenants' care plans, often resulting in the agendas of community integration and relationship network development being either a low priority or going unaddressed entirely.

3. A tendency to assume significant functional competence implies an equal level of social competence also exists leads to staff refusing to offer support to tenants around pursuing relationships or becoming more involved in community activities.

4. The selective use of persuasion and encouragement with tenants, focused on largely functional issues, results in the adoption of a *waiting to be asked* approach by staff to dealing with tenants' needs around community integration and relationship network development.

5. The lack of time taken to think about *why* certain approaches to support are being taken rather than others, and to evaluate *how effective* such approaches are in practice, results in support patterns mirroring those of the past and taking on a primarily 'care' emphasis.

==========

Attitudes/Assumptions

1. The presence of the large project provides a ready-made social circle and community for tenants which results in staff being more able to adopt an attitude of complacency toward the need to work on relationship network development.

2. The *walk before you run* mentality held by staff causes them to view community integration and relationship agendas as a future priority rather than immediate to their present work, and this is exacerbated by their tendency to apply this *walk before you run* model of readiness to the tenant group as a whole, rather than to individuals.

3. An ingrained preference for non-involvement in the social activities of tenants, either dictated by the permanency of inadequate staffing levels or an assumption that the absence of their involvement can only benefit tenants, leads staff to avoid or withdraw from opportunities to be present with tenants in the activities or places where new relationship development is possible.

4. The presence of attitudes which resist proactivity and intentionality by staff in assisting tenants to develop new relationships, leads to an absence of investment in, and responsibility for, relationship network and community integration outcomes that evolve (or do not evolve) for tenants.

5. Negative attitudes and assumptions toward both tenants and members of the wider community, despite evidence to the contrary, underlie and reinforce staff's resistance to intentionality.

Please Turn Over

PROJECT STAFF TEAM "B"

Activities/Actions

1. Attention to meeting tenants' need for opportunities to socialise through efforts to co-ordinate *intra-project relationships* and *group social outings* for tenants outweighs efforts to assist tenants to develop relationships beyond the project.

2. The predominance of a home-based, functional independence agenda is reflected in both the staff team's priorities and the tenants' support plans, often resulting in agendas of community integration and relationship network development being either a low priority or *going unaddressed* entirely in the day-to-day support that is provided.

3. The tendency to 'add' available integrated opportunities to people's weekly agenda *only if there is a gap* in their schedule means that people are not given the opportunity for choice, and the opportunity to leave segregated activities behind.

4. The selective use of persuasion and encouragement with tenants, focused on largely functional issues, results in staff saying they would address relationship network and community integration issues *if tenants asked* for this, while they are more likely to intervene without being asked on more functional issues.

5. The lack of time taken to think about the quality and nature of tenants' relationship networks, results in staff being unaware of just *how tenuous or unsatisfactory* particular tenants' relationship networks are, and consequently this situation goes unacknowledged and unaddressed.

==========

Attitudes/Assumptions

1. The presence of the large project provides a ready-made social circle and community for tenants which results in staff being more able to adopt an attitude of complacency toward the need to work on relationship network development.

2. When pressed about the need for positive relationship development, staff adopt a rose-coloured glasses perspective about tenants existing relationships.

3. When pressed about the need for positive relationship development, staff fall back on the fact that people have a busy life implying this is a substitute for quality relationship networks.

4. The presence of attitudes which resist proactivity and intentionality by staff in assisting tenants to develop new relationships, means hopeful beginnings are left unpursued, unless a crisis or need on staff's part arises, at which point an intentional approach is made.

5. Underlying much of the apparent resistance to intentionality are negative personal attitudes toward both tenants and members of the wider community. despite staff clearly providing evidence to the contrary.

6. Complacency around integration, and the importance of this in providing opportunities for tenants to extend their relationship networks, evolves from the availability of a variety of segregated opportunities to which tenants can gain easy access and for which they do not need staff support to attend. In some cases, staff will go so far as to encourage providers of these segregated options to provide *more* rather than to find ways to offer more integrated options.

Please Turn Over

PROJECT STAFF TEAM "C"

Activities/Actions

1. Emphases on promoting positive *intra-project* relationships and on *maintaining* existing relationships lead to staff efforts being most restricted around developing *new* relationships *beyond the home*, while staff are more likely to define aspirations for tenants' relationship network development in terms of existing relationships, even where time suggests such relationships (particularly those involving other people with intellectual disabilities) are not likely to evolve.

2. The use of persuasion and encouragement in maintaining and developing tenants' relationships with other people *who have intellectual disabilities*, and to facilitate *participation in organised activities*, while not adopting a similar approach around tenants developing new or existing relationships with people who *do not* have intellectual disabilities.

3. Teaching agendas focused exclusively on the home and functional skills acquisition distracts staff from planning and trying out community integration strategies, causing staff to remain 'stumped' on how to facilitate relationship development and get beyond awareness of the poor networks that exist for tenants.

4. Adopting a passive approach to the facilitation of relationship networks and community integration, demonstrating both a *'waiting to be asked'* mentality and a *resistance to intentionality*; in particular, staff fail to pursue and productively shape initially positive attitudes of community members toward the tenants.

5. Integrated opportunities that tenants are supported to undertake are not primarily intended to help tenants to meet new people and potentially form new relationships; therefore, support for participation does not actively address new relationship development, and participation ends for other reasons, even when the potential for new relationship development and community integration is high.

==========

Attitudes/Assumptions

1. An awareness that staff's presence may be a barrier to social opportunities for tenants results in staff adopting a short-sighted *preference for non-involvement* which seems to create equal barriers to relationship development.

2. When pressed about how to address the fact that relationships with the wider community have not developed, staff express a *cynicism* about how far intentionality would be successful, despite acknowledging that experience with community members suggests this would work and acknowledging that citing community resistance may often be an 'easy' (& invalid) excuse for inaction.

3. The combination of a defensive attitude toward the wider community, which appears to be an unfair 'grudge' held by staff and based on early negative reactions to the project by a small section of the community, and a protectionist attitude inherited from the agency causes staff to feel they are the best network of support for tenants and consequently disregard the facilitating relationship development.

4. An assumption that there is basic but unspoken agreement among staff about their expectations for what tenants should gain from community participation means these expectations are not explicitly clarified and support offered for tenants to participate is not consistent.

Please Turn Over

PROJECT STAFF TEAM "D"

Activities/Actions

1. Focusing on *intra-house* relationships, which often includes mediating in disputes and jealousy between tenants, as well as encouraging tenants to go out together in order to compensate for the lack of available staff support.

2. Concentrating on *maintenance* of existing relationships, particularly trying to maintain tenants' relationships with other people with intellectual disabilities when little motivation is shown by the tenants, is contrasted by the lack of efforts to assist tenants to develop new connections.

3. A tendency to react to tenants' inadequate relationship networks by making referrals to formal befriending programmes or by asking adult training centres and social workers to address the need for new relationships, while undertaking no initiatives of their own in this regard.

4. Being drawn into the busy trap, focusing on connecting tenants to places and activities, rather than to relationships (particular people within these places and activities), which ultimately resulted in tenants developing no new relationships through their participation.

5. Adopting an emphasis on promoting full independence, despite acknowledging that this would be unlikely for many tenants, which results in largely functional agendas becoming the accepted priority and eating up the bulk of staff time, thereby crowding out the relationship network and community integration needs of tenants.

6. A tendency to lack sufficient knowledge of tenants networks beyond the home (e.g.. when attending ATC's or staying with relatives) to enable staff to offer effective support for developing potential relationships when not at home.

==========

Attitudes/Assumptions

1. The lack of vision about strategies staff could use to assist tenants in developing new relationships, and the lack of awareness of how their own personal networks and connections could be a starting point for this work, results in staff adopting *an attitude of resignation* toward their ability to facilitate more positive relationship networks for those they support and *a cynicism* about the possibility of natural introductions, as a basis for new relationships, being available to tenants.

2. Negative assumptions about members of the wider community, based on the less-than-positive results of limited and wholly impromptu contact, results in the staff team doing nothing to encourage more positive relationships or involvement locally for tenants. Staff appear to adopt instead a "keep ourselves to ourselves" attitude, leaving them and the tenants feeling isolated, despite residing in a busy urban community.

3. Assuming that the variety of 'presenting problems' that tenants struggle with are primary, rather than recognising that the evidence suggests these are really a manifestation of the absence of positive relationship networks, causes staff to focus on treating the symptoms rather than the real source of tenants' troubles.

4. Where tenants' need for support in extending their social lives and relationship networks is far greater than their need for support in more functional life areas, staff presume that it is the tenants' lack of social competence that is the primary barrier, rather than the inadequate support offered by staff.

Sample Staff Interview Questionnaires

Interview One Questionnaire

Introduction of Major Focus of Research (a)

Reintroduce general explanation of research - discuss my focus on the process of community integration. Explain first interview about personal experience and its relevance to overall study...

a. your own sense of community integration
b. the agency's expressed sense of community integration
c. the experiences and sense of community integration for the people you and the agency support.

Explain the need for a definition of "community integration" and introduce my definition: feelings of security and belonging. (HANDOUT)

Clarify that this is a universal definition - applicable to all people regardless of ability or disability. Ascertain a degree of understanding of this definition.

Do you agree or disagree with this definition of community integration? Is this what you feel your own community integration is dependent upon?

Is there anything else you would add as also an important component of community integration?

What are the things that are a part of your lifestyle that contribute to your feelings of security and belonging.

What part do your various relationships play in supporting your feelings of security and belonging?

Personal Meanings of Friendship and Relationships (b)

INTRODUCTION OF PROTOTYPE CATEGORIES of relationships my research will be concerned with. (HANDOUT)

Think about the people in your life - at work; in your neighbourhood/town; at home; in your social life; in your family. Read each prototype and for each one, list the people (adults/16+) who you have a relationship with (up to 5) that you feel fit into the category.

Now that you've done that, tell me how many people you listed in each category:

a. Intimate Friend: _____
b. Friend: _____
c. Social Acquaintance: _____
d. Relative: _____
e. Professional: _____

LIST OF SCENARIOS

Now, with all of these prototypes in mind, I'm going to read a list of scenarios in which you may require assistance from someone else. For each one, I'd like you to think of the person you would go to first and tell me which prototype he or she falls into. Then do the same for the person you would go to second.
**If the person you are thinking of is a neighbour or spouse/romantic partner, please tell me that specifically.

**If the person you would go to has not been listed, try to
^LWarning: Already beyond next tab stop
decide which prototype he or she would fall under and tell me which that is.

Questions about an Intimate Friend (c)

How important is having an intimate friend(s) to you? Could you explain why you feel this way?

If you are involved in a romantic relationship, but not married, do you consider your partner an intimate friend? Why or why not?

Are there any other people (prototypes) who are more or equally important to you than an intimate friend? If yes, who? and why?

How often do you see/communicate with your intimate friend(s)?

How do your intimate friends and friends effect your self-confidence/happiness?

Experiences with the Development of Relationships (d)

Can you recall how your intimate friendship(s) got started?

Going back to the people you listed under "Adult Relative" - since relationships with relatives (except spouses) happen by inheritance - not choice, would you tell me, for each relative you've listed, if you feel the relationship is based to a greater degree upon: a. familial obligation;
b. feelings of friendship - you keep the relationship going because you get something out of it.

1. _____
2. _____
3. _____
4. _____
5. _____

WILMOTT

According to one author, there are four things necessary for the development of new relationships:
opportunities
skills
motivation
mutual attraction

Could you tell me what you think he means by each of these categories?

opportunities:

skills:

motivation:

mutual attraction:

Is any one category more important than the others? Why?

Do you think that the people with intellectual disabilities who you support have the same need for these four things that non-intellectually disabled people have when developing new relationships? YES or NO Why or why not?

Is any one category more important than the others for the intellectually disabled people you support? If yes, which one and why?

CONCLUDING REMARKS (e)

Do you think that having a network of relationships has helped you in your own community integration - your own feelings of security and belonging?

Do you think a network of relationships does or would contribute to the community integration (feelings of security & belonging) of the intellectually disabled individuals you support? YES or NO What makes you believe this?

STAFF INTERVIEWS #5 - TRANENT, SEPTEMBER 1994

REVIEW OF CURRENT RELATIONSHIP NETWORK

*give staff member copy of prototype definitions.

Give staff copy of post-move #3 relationship network (from last time)
*Discuss losses.
*Discuss promotions or demotions.
*Discuss changes in intesity of relative relationships.

Reason (staff involved in any way?)
Positive or Negative

*Discuss and categorise each new addition, using the prototype definitions.

How came about?

Staff involved in any way?

Positive or Negative addition?

EVALUATING OVERALL QUALITY OF FINAL RELATIONSHIP NETWORK AND LEVEL OF COMMUNITY INTEGRATION

Thinking about _____'s current relationship network - 2 1/2 years after the move from Prestonkirk, what would you say are :

a. The strengths/positive points of the network?

b. The weaknesses/negative points of the network?

Recalling my definition of community integration, (handout) feelings of security and belonging, would you still agree with this definition? If no, what would you say community integration is about now?

What would you say ELCAP's definition of community integration is at this point?

Thinking about _____'s experience of community integration in terms of this definition, does _____ experience:

a. Feelings of Security? YES OR NO
If yes, how can you tell - what is the source?

b. Feelings of Belonging? YES OR NO
If yes, how can you tell -what is the source?

Assuming that achieving community integration is about having feelings of security and feelings of belonging that come from relationships with other people, would you say that helping tenants achieve community integration is part of your job currently?

Which part - security or belonging - would you say that you spend the most time on helping tenants achieve? Could you give some examples? Why this part?/Why not the other?

Are you satisfied - 2 1/2 years after the move - with the amount of progress the tenants have made in achieving community integration as I've defined it - feelings of security and belonging?

If no, why not?

LOOKING AT NEW FRIENDSHIP DEVELOPMENT IN PARTICULAR.
ACTIVE ROLE FOR STAFF IN RELATIONSHIP DEVELOPMENT

1. In reviewing the lifestyle and patterns of activities that the men are involved in, there appears to have been significant growth in this area. Although the staff group has voiced concerns about the fact that local activities, related specifically to the men's interests, are not always easy to find, the men seem to have quite busy schedules. There is certainly an increase in activities as compared to when they lived in Prestonkirk. Many of these activities are regular events, like groups they belong to or classes that meet regularly.

   With all of this, one might expect that some friendships might be developing. It appears to me that a handful of social acquaintances have come from involvement in these various activities, although if the regular activity stops, further contact with those who were also involved has not been likely.

   You'll recall when we talked about Wilmott's four factors necessary for developing relationships - opportunity, skills, motivation, mutual attraction. Most staff agreed that opportunities were most important of the four factors when we first talked about it. Given the current lifestyles of the men, would you agree that opportunities for developing relationships are high? YES OR NO If no, why not?

Looking at the networks over time, particularly the new additions, it seems that the men have not developed very many new friendships with community members through their varied lifestyles. Do you agree? YES OR NO

Would you agree that it appears as if providing opportunities to socialise or interact with new people is not enough to cause friendships to develop? YES OR NO

Let's try to find the missing link? Lets consider the Willmott's other three factors - skills, motivation, mutual attraction.

Anthing to do with having the wrong, or inappropriate, skills?

Anything to do with a lack of motivation?

Anything to do with a lack of mutual attraction?

Anything else?

How about staff's role in tenants developing friendships. In the past we've talked about the importance of staff's role in doing this, and how important staff are when people have limited networks of relationships. You've obviously been working hard on providing opportunities. But still, new friendship development with community members has been limited. Is there anything else staff could/should be doing to increase the likelihood that the men have the opportunity - not just to meet people - but to pursue relationships beyond social acquaintance if they want to?

What should the staff role be in filling that missing link between opportunities to meet people and making friends?

How directive should it be? Why? Give an example to illustrate.

Are staff filling this role now? YES OR NO If no, why not?

Prompt: Is there something 'unnatural' about direct and active intervention/support/guidance in relationship development? (either to start new relationships or to help existing relationships progress) What is this about??????

RELATIONSHIPS WITH PEOPLE WITHOUT LEARNING DIFFICULTIES

It is certainly not true that the men are isolated. Indeed they are almost in the constant company of others. The men also have relatively close relationships with other people with learning dificulties, which provide them with some security. So do the men need friendships with people who do not have a learning difficulty? YES OR NO Why?

Do the men show signs of being keen for relationships with people without learning difficulties? YES OR NO Evidence. (vol - meet and quickly become identified as friends)

Why do you think this is - what is it that they might hope to gain from these relationships that they don't get from the relationships they already have?

We talked earlier about some of the reasons why the men have not developed many friendships from the activities they are involved in. Do you think that people without learning difficulties are in any way reluctant to form relationships beyond S.A. with the men? YES OR NO

Can we talk about the source of this reluctance. What are the reasons why people might not want to get to know people with learning difficulties?

PROMPTS: attitudes generally toward disability
afraid of overdependence - being a substitute for staff rather than alternative
health risk - responsibility
its not their job.
not willing to help anyone they don't know or only know as an acquaintance regardless of disability or not

EXAMPLES FROM YOUR EXPERIENCE?

Should staff try to create a climate of good neighbourliness among community members? In other words not only encourage tenants to be good neighbours but also community members? How should they do this? EXAMPLES What are the dangers/obstacles of doing this?